

**THE JOURNEY TOWARDS NETHERNESS:
EXPLORING ENDOMETRIOSIS EXPERIENCES IN AND THROUGH AN
IMPROVISATIONAL CREATIVE PRAXIS**

By
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Dedication

I dedicate this work to the women who so courageously shared their endo stories with me:

Jessie, Toby, Chelsea, Mei, and Danielle

&

To the women whose pain and more importantly, whose strength and creativity, I inherited:

My mother, Nancy and my grandmothers, Patricia & Carol

Acknowledgements

This vulnerable, consuming project would not be realised without a support system of many people contributing time, energy, and kindness. I am grateful for family, friends, collaborators, and peers who extended themselves in such generous ways. In particular, I thank my husband for being my endless champion; my son for being a source of healing, comfort, and inspiration; my family and friends for never doubting my body, resilience, or ambition; and my fierce allies, Dr. Daniel Kort and Dr. Amir Marashi, who have not only always treated me with empathy, respect and skill, but who, through this process, have become trusted friends and peers. Finally, I extend my heartfelt gratitude to my advisors, Professor Vida Midgelow and Professor Christopher Bannerman: their brilliance, unwavering encouragement, confidence in me, and insightful guidance have given me immense strength throughout this journey.

Abstract

The Journey Towards Netherness: Exploring Endometriosis Experiences in and through an Improvisational Creative Praxis

By Kate March

Monthly disabling pelvic and back pain; burns from heating pads on the abdomen; years of untreatable migraines; a decade of suffering before diagnosis; seven surgeries; multiple organ removals; four rounds of IVF; visible and invisible scars; litres of red, black, and brown blood. These depictions reveal my ongoing, ever-fluctuating journey with endometriosis. My experiences with this debilitating and incurable disease echo the clandestine torment endured by one in ten women (including individuals assigned female at birth who might identify otherwise).

Inspired by veiled narratives of female pain, this doctoral research explores lived-body experiences of endometriosis through a methodological framework which connects improvisation with theory from feminist and disability studies. Specifically, the research expands concepts like maternal interruption, disorientation, and dissonant disability to encompass the female pain experiences of endometriosis. Considering these linkages, the practice focuses on exploring collaboration, cripp time, and an improvisational presence (including embodied strategies like somatic consciousness, adaptability, or reverence for the unknown).

Through solo art-making and a series of interactive exchanges with five other endo sufferers, the research discovers novel insights, language, and articulations related to this condition. Over time, and through a dynamic interplay between theory and practice, individual and collective pain journeys were woven into an exploratory body of work which contains small painting studies, narrative and reflective writing, performance art films, and movement improvisation studies. Eventually, the research practice culminated in a live-art concept entitled *Nether Space(s)*, a painscape which blends body-painting, poetry, dance, and an original sound-score.

Additionally, the research's accumulating insights yield a pivotal revelation: the concept of netherness. Netherness serves as a framework for shifting or 'cripping' art-making and life practices to honour and reflect the realities of navigating endometriosis pain. Its creative threads include embodied dissonance/liminality, non-vertical spatial orientations, and unconventional energies or temporalities. Experimenting with and refining these endo-centric idiosyncrasies was integral to the unfurling of *Nether Space(s)*.

In disseminating the evolution of *Nether Space(s)* and the inception of netherness, this thesis becomes a testament to the creative power of engaging with the disruption, disorientation, invisibility, and scars of endometriosis. Through critical writing, introspection, poetry, photography, and film documentation, the capacity of endo-centric artistic research to provoke, empower, connect, and transform is unveiled.

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*Please note that this thesis includes extensive documentation of creative practices ([Appendix C](#) provides links to the comprehensive artistic portfolio). For the sake of clarity, the creative practices and outcomes documented in Chapters 3 and 4 played a crucial role in the doctoral project; presenting them alongside text provides an opportunity to engage deeply with the research journey in its entirety. However, the visual and video content within these chapters is not being submitted for examination. The final artistic outcomes and practices submitted for examination are:

- I. **Kinaesthetic Painting Performances & Artwork** (detailed in Chapter 5, with additional raw footage video links included in [Appendix A](#)).
- II. **The Performance/Exhibition entitled *Nether Space(s)*** (detailed in Chapter 5, with additional live excerpt links included in [Appendix B](#); the full video link can be found in Chapter 5 and for convenience, in [Appendix C](#)).
- III. **Various poems** interspersed throughout the thesis which offer a different mode of articulating the research (notably in the Introduction, Chapter 3, Chapter 5, and Conclusion). Some of the poems arose from my lived experiences while others arose from exchanges with collaborators.

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Chapter 3

Figure Number	Chapter	Page Number	Date	Descriptive Text
1	3	56	January 2021	A woman sitting on the floor with her hand covering her face. The setting is a small living room with a couch and pillows. This image is a screenshot from a creative practice, movement, or performance video.
2	3	57	January 2021	A woman in a deep squat position with her head down, holding her head with one hand. The setting is a small living room with a couch and pillows. This image is a screenshot from a creative practice, movement, or performance video.
3	3	58	February 2021	A woman with the torso half of her body lying on a sofa while her bottom half of body is extended off the sofa. Her legs are bent and feet flat on the ground. Her hands are raised with tension in her fingers. The setting is a small living room with a couch and pillows. This image is a screenshot from a creative practice, movement, or performance video.
4	3	59	February 2021	A woman standing and bending forward with her hands clasped together. She appears to be in a stretching or contemplative pose. The setting is a small living room with a blue couch and pillows. This image is a screenshot from a creative practice, movement, or performance video.
5	3	59	March 2021	A pregnant woman lying on her back on a patterned rug, hands are clasped, arms are bent, and one knee is bent while the other leg is straight. The setting is a small living room with a couch and pillows. This image is a screenshot from a creative practice, movement, or performance video.
6	3	60	March 2021	A pregnant woman in a low squat position, leaning forward with her hands on her knees, wearing a top and leggings. The setting is a small living room. This image is a screenshot from a creative practice, movement, or performance video.
7	3	61	January 2021	Abstract painting with bold red and pink curving strokes on a black background.
8	3	62	February 2021	Abstract painting with circular forms in pink and red hues and a single black stroke of paint disrupting the right side of the painting.
9	3	63	March 2021	Abstract painting with swirling red and pink circular shapes on a purple and black background.
10	3	63	April 2021	Abstract painting with entangled pink, dark purple, dark blue and red swirls and shapes reminiscent of the internal body cavity or intestines.
11	3	64	May 2021	A pregnant woman sitting in a chair holding a painting with abstract red and pink swirls, near a window. This image is a screenshot from a creative practice, movement, or performance video.
12	3	65	March 2021	An abstract artwork featuring red yarn wrapped around a dark, textured background, creating an intricate pattern.
13	3	66	March 2021	An abstract painting with deep purple and red shapes, partially wrapped with black yarn, creating a layered effect.
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16	3	69	April 2021	A pregnant woman in a long blue dress with red yarn wrapped around her body, holding her belly. The setting has blue lighting. This image is a screenshot from a creative practice, movement, or performance video.
17	3	73	April 2021	An abstract painting incorporating poetry text written in black ink. The paint creates various shapes in red, purple, and black. The text is outlined in black ink as well to draw attention to the words.
18	3	73	April 2021	An abstract painting with blots and swirls of purple and red, with the word 'aching' written multiple times in the white space of the art.

Chapter 4

Figure Number	Chapter	Page Number	Date	Descriptive Text
19	4	90	December 2021	A woman partially covering her face with both hands. The partial eye contact gives the impression of a sombre mood. The setting is dark like a black studio space. This image is a screenshot from a creative practice, movement, or performance video.
20	4	90	December 2021	A woman in a seated position; knees bent with her head down and hands gripping her head/hair. The setting is dark like a black studio space. This image is a screenshot from a creative practice, movement, or performance video.
21	4	91	January 2022	Split-screen image of two women improvising in separate rooms during a zoom session. One in a bedroom and the other in a living room. These images are screenshots from creative practice, movement, or performance video.
22	4	92	January 2022	A woman kneeling on a dance studio floor with her head down, surrounded by red yarn. The setting is a brightly lit room. This image is a screenshot from a creative practice, movement, or performance video.
23	4	92	January 2022	A woman lying on a white bed, entangled in red yarn, pulling at the yarn with a pained expression. This image is a screenshot from a creative practice, movement, or performance video.
24	4	93	March 2022	Close-up of a woman's leg wrapped in ripped red tights and red yarn. This image is a screenshot from a creative practice, movement, or performance video.
25	4	94	March 2022	Close-up of a woman's hands holding red yarn against her chest. This image is a screenshot from a creative practice, movement, or performance video.
26	4	95	March 2022	A woman standing against a white wall, facing away from the viewer, wearing a black dress with an open back. This image is a screenshot from a creative practice, movement, or performance video.
27	4	97	April 2022	A mirrored image of a woman lying down, creating a symmetrical and haunting effect. The image is in grayscale. This image is a screenshot from a creative practice, movement, or performance video.
28	4	98	May 2022	A woman screaming in a mirrored effect creating an unsettling connected torso. There is red yarn hanging in the background. This image is a screenshot from a creative practice, movement, or performance video.
29	4	100	April 2022	A woman leaning against a wall facing the corner. She is wearing a sheer black top and blue skirt. This image is a screenshot from a creative practice, movement, or performance video.

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31	4	103	September 2022	A woman on a dimly lit stage, performing a stooped over movement with bent legs. This image is a screenshot from creative practice, movement, or performance video.
32	4	104	April 2022	Bold abstract painting with splashes of blue, red, and black on a white background. Two black handprints are seen in the background.
33	4	105	May 2022	Abstract painting with vertical red streaks resembling a handprint.
34	4	106	April 2022	A woman with back to the camera, wearing a blue skirt and sheer black top, arms raised as if climbing a white wall. This image is a screenshot from a creative practice, movement, or performance video.
35	4	107	March 2022	Abstract painting with chaotic black lines and red paint dripping down.
36	4	107	March 2022	Abstract painting in black swirling forms and patterns on a white background. Almost reminiscent of an ultrasound of an uterus.
37	4	108	May 2022	Hand-painted text with the words "I am broken, I am whole" written in black on a white background.
38	4	109	August 2022	Sketches of a woman in various poses with red markings on her body and handwritten notes around her.
39	4	110	August 2022	A woman standing outdoors, wearing a white dress tied with red yarn. This image is a screenshot from a creative practice, movement, or performance video.
40	4	111	August 2022	A woman standing outdoors, reaching up towards a tree branch, wearing a white dress tied with red yarn. This image is a screenshot from a creative practice, movement, or performance video.
41	4	112	May 2022	A woman wrapped in black yarn standing against a wall covered in more black yarn. She has a mask made of flowers covering her face. This image is a screenshot from a creative practice, movement, or performance video.
42	4	112	July 2022	A woman bending over standing upon a white canvas. She is masked and wearing a black leotard, red tights, and high heels. This image is a screenshot from a creative practice, movement, or performance video.
43	4	113	January 2022	Abstract painting with several distinct splashes and drips of red paint on a white background.
44	4	114	January 2022	Abstract painting with white splashes on a dark background creating an image loosely related to the female reproductive system with ovaries, fallopian tubes, and uterus.
45	4	115	March 2022	Abstract painting with layered splatters of dark blue and black paint on a white background.
46	4	115	June 2022	A woman wrapped in a blue fabric, standing in front of a wall with abstract paintings connected by red yarn. This image is a screenshot from a creative practice, movement, or performance video.
47	4	116	July 2022	A woman with her face obscured by cascading white yarn, in a room with dark lighting. This image is a screenshot from a creative practice, movement, or performance video.
48	4	116	July 2022	A woman in a white outfit holding a white wig, sitting in a dark studio space with red/amber lighting. This image is a screenshot from a creative practice, movement, or performance video.

49	4	118	August 2022	A woman with a white wig, facing away from the camera, standing in front of a decorative glass door. This image is a screenshot from a creative practice, movement, or performance video.
50	4	121	March 2022	A mirrored image of a woman with red yarn wrapped around her head and upper body, creating a split/twin effect. This image is a screenshot from a creative practice, movement, or performance video.
51	4	121	March 2022	Close-up of a woman's hands wrapped in red yarn, wearing a black outfit. This image is a screenshot from a creative practice, movement, or performance video.

Chapter 5

Figure Number	Chapter	Page Number	Date	Descriptive Text
52	5	123	August 2023	A woman standing in a room filled with red yarn and various paintings on the walls and floor.
53	5	125	August 2023	Five bodysuits laid on a colourful floor, each painted differently in shades of blue, black, and red.
54	5	126	August 2023	A woman in a beige dress bent forward with arms outstretched, performing in a gallery space. The image is a screenshot from video content.
55	5	126	August 2023	A woman in a beige dress kneeling on the floor, writing on a large white canvas. The image is a screenshot from video content.
56	5	127	August 2023	Close-up of a woman's midsection with hands pressing black paint against a bare back. The image is a screenshot from video content.
57	5	128	August 2023	A woman in a performance space screaming with hands on her chest, a large painting in the background. The image is a screenshot from video content.
58	5	128	August 2023	A woman with her body and face painted in red, looking directly at the camera.
59	5	130	August 2023	A large abstract painting with a mix of purple, red, and white colours.
60	5	131	August 2023	A large abstract painting with a mix of black, dark blues, light purple, pink, and flashes of red.
61	5	132	August 2023	A large abstract painting with a mix of black, dark and light purple, different shades of red, and some white on display.
62	5	133	August 2023	A large abstract painting in red and pink hues with swirling and bold brush strokes.
63	5	134	August 2023	A large abstract painting featuring a gold circle on a dark, textured background.
64	5	135	August 2023	A large abstract painting with dark, rich hues and a burst of golden light in the centre.

65	5	144	May 2023	Screenshot from a zoom dance rehearsal, featuring three dancers.
66	5	145	July 2023	Two women rehearsing in a studio, one in the foreground and the other in the background. The image is a screenshot from video content.
67	5	145	August 2023	Three dancers in silhouette performing in a gallery with large windows in the background. The image is a screenshot from video content.
68	5	147	August 2023	A woman bending backwards in a gallery performance, audience seated around her. The image is a screenshot from video content.
69	5	148	August 2023	Three dancers in matching outfits performing synchronised movements. The image is a screenshot from video content.
70	5	148	August 2023	Three dancers in a circle bending over holding their midsections in a gallery performance. The image is a screenshot from video content.
71	5	149	August 2023	Three dancers facing outwards in a circle with fingertips touching, performing in a gallery. The image is a screenshot from video content.
72	5	150	August 2023	A group of dancers performing, heads down and stooped over position in a gallery space. The image is a screenshot from video content.
73	5	150	August 2023	Three dancers in intense, energetic movement, hair flying, in a gallery performance. The image is a screenshot from video content.
74	5	151	August 2023	Three dancers lying on the floor in a gallery, arms outstretched. The image is a screenshot from video content.
75	5	152	August 2023	Close-up of a dancer with pink hair screaming during a performance. The image is a screenshot from video content.
76		152	August 2023	Three dancers in foetal positions on the floor, performing in a gallery. The image is a screenshot from video content.

INTRODUCTION: WHAT ENDOMETRIOSIS HAS TAKEN; WHAT ENDOMETRIOSIS HAS GIVEN

The Inspiration

I.

I got my first period

On Mother's Day.

I remember

The look on

My mother's face

But I don't remember

The innocence

Of not feeling pain.

My first GYNO appointment

Was soon after:

My school absences

Piled up.

Each month became

A new physical reckoning

Testing my pain threshold.

My first time

In stirrups

I was so young;

It was nauseating.

The cold metal

Pushed inside my body

In that sterile exam room,

I was in a living hell.

Now, I'm acclimated —

A reality I know all too well.

That first doc put me

On the pill

Without further investigation.

I hated those fucking chemicals.

The cramps

Hardly diminished

Instead, my personality did.

I felt numb--

A shadow of myself.

*I still have
This image of the family
Dog sitting with me,
Licking my face
To comfort me.*

I am a woman living with endometriosis. For years, my healthcare was mismanaged and I battled this invisible condition without consideration, validation, care, diagnostic exploration, and ultimately, without treatment. I have comprehensively paid an exorbitant price as a result of my severe pain and chronic disease experiences being spurned for so long. With my suffering silenced, my body's full story was hidden. I perpetually sought medical explanations from doctors only to be met with disdain. When physician after physician paid no serious heed to my pain, I felt increasingly, thoroughly disregarded. My very real pain was perceived as a product of an active imagination; *hysteria* is the word they used less than a century ago. The waves of shame came, implosive and destructive. In my circumstances, the absence of diagnostic exploration for so long meant, in the context of healthcare, an absence of legitimacy, and so too, the lack of an actionable treatment plan — a shared trajectory with many other women. Without tools to forge a path towards healing, the torments of endometriosis ravage, sabotage, wound and scar. Seven surgeries later and following the pregnancy and birth of my IVF-conceived son, I reflect on the interruptions, destructions, transformations, and indeed, creations this disease can thrust upon a life.

Through both poetry and prose, this introduction reveals the irony of my body: it remains an invaluable instrument for creativity and joy despite being a source of challenge, frustration, and anguish. As a professional performance artist and dancer, I have perpetually depended on my body as an important, if not the most essential, channel and vehicle for my artistic expression. Working in this realm has taught me the power of both expressing with and listening to bodies. As a result, I trust my body even in the darkest of moments; even when I am enduring endometriosis symptoms and feel consumed by a sense of betrayal. Art-making, performing, and sharing my artwork with audiences around the world has nourished me in times of brokenness and in times of recovery. This deep-seated trust in the artistic process as a space and time for both brokenness and wholeness or light and darkness became even more pronounced in fulfilling this research project's purpose and intentions.

II.
*I sat
On the toilet,
Naked and screaming
As my body shook
Feeling my period's arrival.
No, the pill certainly
Was no remedy
For this dark disease.*

*Sometimes, when
 I was younger
 And afraid to be alone
 With my uterus,
 I would phone my Nana
 To come over
 With her heating pad
 In hopes of providing me
 Some relief.
 Her presence
 Took some edge off.
 During those years
 I dipped into
 Many different chemicals
 At the bequest of doctors.
 Migraines and moodiness
 Was all I got in return.
 I try to block out
 Those early
 Bloody days.*

The Purpose

In artistic experiences, my body and art communicate and for the most part, the audience listens or receives attentively. In contrast, in pain experiences, my body speaks to me and I listen, but as I try to share what it is saying, my words fall short to audiences of highly trained medical practitioners as well as peers or family. This contradiction is evidenced in the first 16 years of my battle with debilitating pain before a doctor finally considered exploring the cause and, therefore, treatment options. Evidently, my voice and words alone, did not convey the depth of my physical and emotional pain to my healthcare providers in a manner that inspired immediate action.

Why was such severe pain repeatedly ignored? Is it because of my gender and the fact that my pain originates in the female reproductive system or predominantly occurs during menstruation? Is it because my expression of pain was misunderstood or misrepresented due to archaic systems of pain description? I am certainly not alone; this is a familiar pattern for millions and millions of women (and individuals assigned female at birth) in pain, and specifically, those with endometriosis.

Over the years, part of becoming my own health advocate has meant familiarising myself with modern approaches and knowledge of endometriosis or related diagnoses (disease details are disseminated in Chapter 1). Because of this, I know firsthand there is a distinct and dire need for more endometriosis-centred research whether it is medical, psychological, sociological, cultural, or artistic. Even I, across my 15-year professional career in performance and art, have avoided the overt and explicit exploration of pain and pain communication in my art-making and process. In the past, I have

merely alluded to my endometriosis pain through the performative embodiment of certain postures and gestures resembling themes around resilience, the overcoming of adversity, or endurance.

III.

*Once, while working
In Taipei,
I found myself in a
Non-English speaking
Health clinic.
I laid down in the
Familiar torture chair.
And rather abruptly,
My vagina appeared,
Magnified on a big screen.
As the instruments entered,
The doctor pointed out
All my anatomical
Lady parts.*

*A throng of nurses watched
As if spectators,
Voyeurs to my discomfort.
I am a science project.
She pointed out 2 cysts
But unsurprisingly,
Indicated no treatment
Or guidance.
I left feeling
Alone,
Defeated.
I went back to the hotel
Clenching my jaw,
Alternating Advil and Tylenol —
Maximum dose
As usual.*

*My college years
Must be buried
Deep, deep, deep.
I still only see
Blurred memories.
I refused more
Birth control pills,*

*Patches or otherwise.
I freed myself from
The prison
Of a hormonally-controlled
Mind and body.
Though, peers
remind me
How often they
Found me
Writhing on the floor;
Enduring nature's
Monthly trauma.*

In striving to unpack the specific and complex explanations for the systemic dismissal, and my own creative avoidance, of female pain, I became increasingly curious about finding contexts or ways in which the lived-body experiences of women and particularly, women in pain, are acknowledged and valued. In commencing this research I sought the places, be it academic scholarship, a book of poems, an art studio, or a doctor's office, where female bodies' stories, particularly involving pain, are shared, seen, felt, and heard. Unfortunately, I discovered such places are too few and far between. In response, this practice research's core purpose was to enhance the communication, comprehension, and expression of female pain experiences¹. Inspired by this broader objective, the research specifically explored alternative ways of expressing lived-body experiences of endometriosis, potentially facilitating their visibility, audibility, and palpability. I pursued this aim armed with an intimate understanding that if people are willing to listen, the body itself has a complex and unique story to reveal and communicate. Similarly I undertook these pursuits with a strong conviction that pain might be expressed through the language of art-making and the arts instead of, or alongside mere verbal representation. Given my particular arts background, I placed emphasis on investigating the communication of pain using an embodied artistic practice in which material and content that have long been a part of my lived-body experience were finally directly called upon.

The Questions & The Tools of Inquiry

My performative artistic practice is rooted in dance, performance art, movement improvisation, and choreography (www.marcharthouse.com and www.iam-dining.com). In the last decade, I have also increasingly experimented with abstract painting/mark-making by applying paint to and with my body; creating dance films; and experimenting with poetry (www.katemarch.com; www.outpour.art;

¹Throughout this thesis, the term 'female pain' refers to pain experiences originating in female biology. While the primary focus of this research is on endometriosis, related experiences may include adenomyosis, polycystic ovary syndrome (PCOS), undiagnosed menstrual pain, premenstrual dysphoric disorder (PMDD), infertility, miscarriage, vulvodynia, pelvic inflammatory disease (PID), chronic pelvic pain, dyspareunia, uterine fibroids, and interstitial cystitis. This is not an exhaustive list, and each experience involves a distinct set of circumstances, characteristics, and treatment pathways. However, these experiences are uniquely associated with female biology and should be acknowledged as implicitly relevant to this research.

and www.thirstofpisces.com, respectively). Most of my projects and collaborations champion the interplay and blending of more than one of these disciplines into a cohesive, multi-layered experience.

Throughout my professional practice, I have repeatedly explored how physicality expresses emotion, memory, taboos, and generally, the hidden and unseen. These patterns are perpetuated and emphasised in this research. As briefly mentioned, my work tends to be thematically curious about the embodiment of triumph; aesthetics of risk, endurance, and stamina; expressions of the multifacetedness of womanhood; and deconstructions of sociocultural conventions of femininity/gender. These themes, while all implicitly related to my pain and suffering, generally have not been direct or conscious expressions of the experience of endometriosis itself. Whether it is through small repetitive movement rituals using paint or intricate full body choreography combined with structured improvisations, I am most interested and experienced in sparking dialogue through the body's languages. Even in my poetry, which is perhaps the least corporeal aspect of my practice, I habitually draw either from physical experiences of the body (as demonstrated throughout this introduction), interact physically with the writing itself, or present the poetry performatively. No matter the form or medium, the innate focus in my artistic explorations remains the female body — its movements, stillnesses, gestures, rhythms, shapes, limits, postures, and experiences.

Similar to the experiential work of artistic collectives like Punchdrunk (<https://www.punchdrunk.com/>) or Third Rail Project (<https://thirdrailprojects.com/>), I often consider the element of audience participation alongside my creative process, establishing possibilities for co-creativity. I produce performance environments and experiences which allow for spontaneous and intuitive interactions to occur between audience and artist; between audience and artwork; or within the audience, site, and artist/artwork. For instance, using structured improvisations, I might integrate: an intimate exchange of eye contact; an opportunity to touch textures of artwork or share the sensation of catharsis; or an unspoken invitation to move or shift rather than sit and watch. In terms of context and site, I almost always have explored intimate physical proximity between audience and performer as a way to blur the boundary between self and other. As a result, my work often favours alternative spaces (dinner tables, art museums, outdoor locations, multipurpose venues) rather than being situated on a stage or in a theatre.

My use of nontraditional performance and exhibition spaces has allowed me to invite audiences into a performative world without traditional barriers (for example: www.aneveningofmeat.com). This general lack of physical boundary has, to a large extent, been the characteristic which has allowed for the subtle yet powerful building of interactive relationships of trust, empathy, and respect between audiences and performers (or in the case of my solo work, audiences and myself). Beyond the physical barrier, a shared space helps elicit a co-creative environment wherein both audience members and artists alike feel empowered to escape into a liberating world of presence, intuition, exploration, and connection. These prevalent qualities within my voice, process and portfolio are relevant to this

project's trajectory and design and are important to bear in mind as tools in the emergence of this research's methodologies, methods, and outcomes.

IV.

*I do recall
When it went
From very bad to
Even worse.
The shock and awe pain
Came when I hit thirty.
I finally realised
My body was
Not always mine.
I projectile puked,
I passed out in alleys,
I dropped to my knees
Begging Gods
And Goddesses
To end my torment.*

*The first surgery,
Removed
The grapefruit size cyst
No white flag for my pain though.
Only a few months later,
Lesions and adhesions
Returned
With a spiteful vengeance.
I grit my teeth and
Tried to make believe
I was healing.
No such luck.*

*A year later,
Deja-vu,
I found myself
Under warm blankets,
Hooked up to the IV
On the surgery bed.
This second lap,
Four treacherous hours.
I'm no longer
A stranger to*

Waking up shivering
And bloated
And bleeding
And groggy
And mad
And dizzy
From surgery.
It's never pretty.

Day by day
I got strong,
Again.
I welcomed
A thought—
Maybe this time
The battle
Is it over?

Then, one night
I woke up
And couldn't move
My insides torqued
And twisted.
I had a kidney stone
Stuck inside of me.
Black lesions
On my ureters.
That stubborn bitch.
It required two surgeries.

Notably, while this research endeavour was artistic in nature, it was never an attempt to create precise representations of endometriosis pain. Instead, in relation to the aforementioned purpose and my artistic identity, my utmost interest was exploring how and what various creative renderings of pain express and divulge in terms of aspects and articulations of the endometriosis experience that might not otherwise have come to light. By using an embodied creative practice as opposed to standard measurements or medicalised articulations of endometriosis pain and by rejecting more traditional pain narrative formats, I hoped to reveal new understandings of the lived-body pain experiences of women as well as new considerations of the nature of art/art-making as a woman with cyclical, chronic, and unpredictable pain.

With improvisation as both conceptual and artistic foundation for communicating and expressing endometriosis, threads and questions emerged, converged, diverged, and evolved over the course of

the research journey. Some resounding questions repeatedly surfacing and steering this project included: What kind of arts practice lends itself to communicating female pain experiences? How might my personal lived-body pain experiences, as well other women's lived-body pain experiences, with endometriosis (and other related menstrual or chronic pain experiences) be expressed through embodied arts processes? What can these embodied creative practices do — both in terms of communicating pain and in the context of producing art? How does using pain as a research material affect art-making decisions in my own creative practice? As I dove deep into the often disregarded pain experiences of myself and numerous other women, I considered other questions more related to an underlying interest in social justice and gender equity: What can I do, in my capacity as both an artist and an individual affected by endometriosis, to advocate for women enduring similar experiences of pain? How might I elevate other women's voices so that their stories of pain are heard, seen, and felt? How can I help other women avoid suffering in silence like I have? Are there 'better' ways to express endometriosis pain?

The overall focus on exploring the lived-body experiences of women in pain draws much needed attention to endometriosis and other related women's health experiences marked by pain. Such topics are, surprisingly, largely absent from existing Feminist Disability Studies (FDS) and Feminist (both existential and phenomenological) literature and topics that, when left perpetually unattended, will continue to inflict tangible repercussions on women's lives (this gap in knowledge is discussed in detail in Chapter 1). I attend to the politics of this research with a distinct audience in mind: the women who suffer from endometriosis or indeed any menstruator whose pain has been downplayed as well as the medical community, family members, peers, or scholars who have encountered yet repeatedly dismissed us. I participate in endometriosis advocacy from the inside out, using art as my path in transforming personal into political.

V.

*Honestly,
Everything happens
For a reason.
Those surgeries,
Number four and five,
Triggered number six.
Because the battle inside
Wasn't finished.
My new surgeon,
Waged his own war
Against the turmoil.
He did his best,
He was a good soldier.*

But another circle

*Around the sun,
The internal terrorism persisted —
I had surgery
Lucky 7.
Doc put up a real fight.
But really,
There is still,
No winning.*

*Pain still forces me
To feel angst
Towards my elegant
Skeleton.
It's not a great look
For a dancer.
I try to smile.
Mostly,
I grit and bear.*

The Journey

Positioning these intentions, questions, and my tools of expertise in an artistic, practice-based territory, this project's theories and practices or methodologies and methods were inherently enmeshed and interactive. The deep symbiosis characteristic of artistic research tends to produce research journeys that are rarely linear, frequently messy, and notoriously resistant to description (Midgelow et al. 2019). Hence, while I attempt to present the research path in a cohesive chronology, this representation cannot fully reflect the dynamic interplay between methodology and methods or theory and practice that occurred. Relatedly, any words or theoretical discoveries shared in this thesis, although distinctly important in their own ways, should be viewed as complementary and digested in connection with the artistic processes and outcomes. Importantly, I champion this research by acknowledging the privileges that allow me to do so, for example: being a white woman in America and having personal economic stability, access to medical care, access to education, strong support systems, and various mental health resources.

In addition, other personal circumstances and milestones bear relevance in understanding the narrative and evolution of this research journey. Initiated during my second trimester of pregnancy, continued through my transition into motherhood during the postpartum phase, and persisting despite disruptions caused by in vitro fertilisation (IVF) related procedures, this journey was marked by significant life events. Although I have chosen not to extensively highlight these particular experiences within my chapters, I am certain they both subtly and overtly influenced the research. Not only did the emotional and physical facets of these lived-body experiences consciously and unconsciously fold into the artistic practice, but their logistical implications often impacted the

research schedule or design. I emphasise particular instances where these influences intersect with the central theme of the research project, namely, the expression of endometriosis. However, for clarity's sake, I largely allow their footprints to remain implicit.

The Chapters

In the written portion of the thesis, Chapter 1 introduces the context of the research by demonstrating the conventional and medicalised ways in which pain and indeed, endometriosis pain and other female pain experiences have been communicated, minimised, and dismissed (Greene et al. 2009; Jones 2016; Nnoaham et al. 2011). Specifically, the research gains interdisciplinary traction as narrative medicine, feminist theory, feminist disability studies (FDS), and the art/art-based practices (namely, painscapes) are discussed in relation to endometriosis and pain expression. The work of contemporary artists using pain, menstruation, or invisible disability as impetus for certain art-making practices will be acknowledged in order to establish the contribution area of this project.

Next, in Chapter 2, a detailed methodological discussion occurs in which I connect conceptual thinking from performance and dance studies (improvisation as life practice) and feminist/maternal studies (the ethics of interruption). Relatedly, the integration of 'crip' identity and theory, a subset from disability studies, is brought to the forefront of this research's methodological philosophy, underlining endometriosis as a gendered disability. Notably, the methodological perspective forged here simultaneously arose from and informed the creative practice and through its ultimate manifestation, the research became increasingly, intentionally framed through a feminist, crip improvisational lens.

In Chapters 3 and 4, I begin elaboration on the artistic research path marked by both independent art-making (Phase I) and collaborative exchanges with five other endometriosis sufferers (Phase II), respectively. These chapters speak in greater depth to the processes and pathways that materialised from the intentional use of endometriosis experiences as material and content. The experimentations with painting; live art ritual; embodied writings in the form of reflective writing and poetry; movement improvisation using embodied pain experiences; dance on film work; choreography; and kinaesthetic painting (paintings created by the body's movement expression) are divulged through a more fluid mixture of critical analysis, reflective writing and artefacts related to the outcomes of the art-making.

Similarly, in Chapter 5, I outline Phase III, the final artistic period of the research. By this point, equipped with a more established sense of the methodologies, various surfacing conceptual and aesthetic themes from the exploratory body of work developed in Phases I and II, and strong content from collaborative exchanges, the final processes and artistic outcomes were completed. Here, the artistic culmination of the thesis, *Nether Space(s)* is described. Elemental qualities of the work, both aesthetic and conceptual, are pinpointed and their relationship to various strands of an original construct denoted as *netherness*, are introduced. In disclosing the nuanced processes involved with

endometriosis-centred creative research, these chapters collectively illustrate new knowledge produced related to the articulation of endometriosis and pain experiences.

In these practice related chapters (3-5), the reader will notice the knitting together of verbal and nonverbal expressions as a representation of the depth and true crux of the research. Stylistically similar to this introduction, discourse blended with woven entries of poetry, reflective writing, and visual aids, together, unveil alternative ways of engaging with and articulating women's experiences of pain, including my own. By offering some theoretical analysis and interpretation alongside descriptions and outputs of the practices, I attempt to reveal how close-knit theory and practice were in this research. Additionally, some readers might find the insertion of artistic expressions alongside critical writing disruptive — an intentional choice to better communicate the concerns of the research and its outputs. At times, the reader may feel certain emotions due to creative interruptions and I invite conscious reflection of these emotions as they surface.

VI.

I didn't know that

One day

I might really

Want a baby

In my life,

In my arms,

In my shattered womb.

The time came—

Angels encouraged me.

My heart listened.

My body didn't.

I found another warrior —

This new, brave doc

Probed and prodded me

For weeks.

Finally, he tells me

What I already knew

From that first Mother's Day:

There is no natural

Way for me to

Conceive babies.

Endometriosis has

taken

taken

taken

*taken**taken**taken**taken**taken**taken**taken**taken**And taken more.***The Destination: Netherness**

As the reader travels through Chapters 1-5 of this thesis, they will be led conceptually and artistically into and through the organic emergence and eventual distillation of a framework designated as ‘netherness’ in Chapter 6. I briefly share its premise here, but the written and artistic components of this project all point to, expand and reveal its inception, characteristics, substance, and capacities as a new tool, and indeed place, to honour female pain. It is an underworld lifted above ground where the stories and bodies of women like mine are honoured without shame and without concealment.

Oxford and Merriam-Webster dictionaries as well as the word’s etymology, suggest definitions of ‘nether’ as ‘down’, ‘below’, or ‘lower in position’. Bearing this in mind, it becomes clear why ‘nether regions’ euphemistically refers to an individual’s genitals or buttocks and essentially, the lower body parts related to reproductive systems. In various religions and cultures, the ‘netherworld’ is synonymous to the underworld, a living hell, or purgatory; the variations all indicative of a dark and uninhabitable place of suffering. Generally, a netherworld or a nether region indicates a place, situation, or part of society that might be considered underground, hidden, unpleasant, and/or ill-defined. This project considers and experiments with all of these meanings in its pursuit to reposition sociocultural meanings around endometriosis or menstrual pain.

Chapter 6 underlines the key aspects of netherness in terms of conceptual theory, artistic process, and aesthetic potential. In this chapter, theoretical ideas that materialised through the practice are discussed, for example: nether liminality, spatial netherness, and nether reorientations of energy, time, and expression. These pinpointed characteristics bound up in the original meanings of nether regions and netherworlds, are reconfigured as evocative and generative rather than unilaterally unfavourable. Indeed, netherness may not always be a comfortably predictable or stable atmosphere to be in, however, this precariousness and uncertainty contain some of its greatest potential in reimagining perspectives on time, space, energy and creativity.

Lastly, I end the written portion of the thesis in the Conclusion chapter. Beyond summarising the journey and the resulting contributions, I discuss the implications of introducing novel ways to express the experiences of endometriosis. I explore how these insights and new concepts can be implemented beyond the scope of this project, using netherness as both a tangible aesthetic and

conceptual tool for shifting a creative praxis or indeed by extension, a life perspective. I touch upon how this research might grow and develop beyond this dissertation by sharing both my personal experiences and my observations of the audience or collaborators. Furthermore, I convey how artistically honouring my own body as well as the lived-body experiences of five other women who suffer from endometriosis became a radical act of healing and a manifestation of resilience in and of itself.

The Invisible Threads

The sticky lesions, twisting adhesions, and accumulating scar tissue seemingly eternally cling to endometriosis sufferers, shaping our experience of the world, even when they are physically excised. This distinctive adhesiveness metaphysically binds me to the disease, to the research collaborators of this project, and in fact, to all of those who have endured endometriosis. We live within the same web, connected by invisible threads which become more visible over the course of this thesis. Through this research, I navigate a path leveraging this notion of enmeshed connectivity between theory and practice or words and art, as an undeniable metaphor for the disease inseparably adhering to body, mind, and spirit — deeper inquiry and then, meaning arises through their attachment. Prominent imagery involving threads and interconnectedness is woven throughout the project both in language and artistic expression.

In consideration of this, I take a moment to prepare the reader/viewer. I acknowledge the potential discomfort and emotional impact of this vulnerable subject matter; engaging with the material herein involves encountering painful and challenging realities. As such, I encourage approaching this content with courage, fortitude, and openness. As we navigate these visible and invisible threads together, may our shared journey foster a deeper sense of connection, collective understanding and solidarity, transcending the confines of these pages and forging a bond that resonates far beyond the confines of this text.

VII.

*I write this
With profound gratitude.
I lost more
Than predicted
Or fathomed.
The floodgates of
Grief
Are always open.
But —
I found hope.
In IVF needles.
In the functional body parts.
In some doctors.*

In many nurses.

In love.

In devotion.

In new chapters.

In empathy.

In the mountains

And the valleys.

The truth is

We can turn

Any devastation

On its head.

By using

Our hearts.

CHAPTER 1: THE EXPRESSION OF PAIN & ENDOMETRIOSIS

Introduction: The (In)Expression of Pain

As mentioned in the Introduction, one of the primary aims of this research is to explore alternative ways to articulate endometriosis experiences and by extension, to communicate, understand, and express the most prominent symptom of endometriosis: pain. The experience of pain, at some point or another, in some magnitude or another, is universally human. However unpleasant or negative, in its most reductive definition, pain can simply be described as a sensation or feeling (Cowan 1968:15). Eminent queer studies/feminist scholar Sara Ahmed points out in her discussion of the politics of pain that the ‘affectivity of pain is crucial to the forming of the body as both a material and lived entity’ (Ahmed 2014: 23-24). It is unsurprising then, that a shared, relatively niche, realm of discourse, has emerged around studying the phenomenon and meaning of pain. Indeed, in many separate yet intersecting disciplines and philosophies various aspects of pain have been researched in a collective attempt to better inform a universal understanding of pain (Ahmed 2014; Morris 1991).

However, across the myriad efforts to comprehend pain, it is regularly acknowledged that the experience of pain is difficult to communicate and nearly impossible to translate into or articulate with language (Bourke 2014; Kugelmann 1999; Werner & Malterud 2003; Scarry 1985). Some scholars argue that pain, perhaps more than any other phenomenon, not only resists language, but also actively destroys it (Charon 2005; Scarry 1985). Pain’s ability to shatter language creates a crisis of expression prompting researchers to question how we might express the deeply personal and varied layers of pain. Conversely, other scholars like Joanna Bourke (2014) and David Biro (2014) argue pain generates new language particularly in its reliance on metaphor and endless attempts to clarify otherwise inexpressible, subjective feelings and sensations.

In recognition of the intricate relationship between pain communication and language, this chapter highlights the necessity of extending language and expression to reflect pain as a complex, multi-layered experience. Turning to a variety of fields, this chapter provides a foray into the study and communication of pain, honing in on meaningful ways to address pain’s resistance to expression. After contextualising the research’s attention to pain by describing endometriosis symptomatology and characteristics in more depth, the chapter focuses on the more conventional ways in which pain in general, and more specifically, endometriosis (and related female pain experiences) has been studied, communicated, or dismissed across various contexts. Namely, those forthcoming sections highlight prominent and relevant pain scholarship in the related fields of healthcare/medicine, medical humanities (narrative medicine), feminist, and feminist disability studies (FDS). Finally, the chapter concludes with a discussion on arts and arts-based research, particularly emphasising the emerging field of painscapes as a compelling domain for this research. In general, this chapter not only establishes distinct references and pathways for creating novel articulations of endometriosis pain, but also sheds light on the disciplines and fields where these articulations could provide meaningful contributions.

Endometriosis: An Experience of Pain

Endometriosis, commonly referred to as endo², is defined as the presence of endometrium-like tissue found outside the uterus (Zondervan et al. 2018). This frequently cited standard medical definition of the disease inadequately represents both the complexity of the symptoms and in general, downplays the various consequences of the disease. Endometriosis is a chronic, incurable, painful disease originating in the female reproductive system, though oftentimes pervading organs throughout the entire body. Impacting 1 in 10 women (Zondervan et al. 2018)³⁴, symptoms cited may include, but are not limited to: dysmenorrhea (painful menstruation); acyclic pelvic pain; abdominal cramping; diarrhoea; painful bowel movements; other intestinal upset at the time of the period; dyspareunia (pain with sex); dyschezia (constipation); dysuria (painful or difficult urination); infertility; somatosensory amplification; and fatigue (Ballweg 2004; Zondervan et al. 2020). The cardinal symptom reported most consistently with endometriosis does seem to be severe pain especially around the time of menstruation (Ballweg 2004: 204).

Unfortunately, the pelvic pain experienced by so many endo warriors⁵ may be inflammatory as well as neuropathic in nature and may persist even after careful excision of the affected tissues due to the disease's long lasting effects on the central nervous system (As-Sanie et al. 2016; Berkley et al. 2005; Carey et al. 2017). Indeed, pelvic pain, unresponsive to conventional treatments, develops in approximately 30% of patients with endometriosis (Shafir et al. 2018). Additionally, an estimated one third of impacted women face infertility which is approximately twice the rate among women without endometriosis (Prescott et al. 2016). These disease characteristics are just a basic overview of the effects of endometriosis on a body. The corporeal experience of symptoms can be devastating physically, and moreover, they affect mental, sexual, social well-being, and productivity making the disease all the more destructive (Nnoaham et al. 2011; Rush et al. 2019).

² Endo is a colloquial term for endometriosis commonly used by those who suffer from the disease. I use endo and endometriosis interchangeably throughout the thesis acknowledging my identity as endo sufferer/advocate in this context.

³ According to the World Health Organization (WHO), around 10% of reproductive-age women and girls worldwide are affected by this chronic condition, translating to roughly 190 million individuals ([World Health Organization \(WHO\)](#)). Similarly, Endometriosis UK supports this figure, stating that 1 in 10 women and those assigned female at birth in the UK experience endometriosis ([Endometriosis UK](#)). These statistics are further corroborated by studies published in prominent medical journals such as The BMJ, which also cite a global prevalence of about 10% ([BMJ](#)).

⁴ It is important to acknowledge that the commonly cited statistic of 1 in 10 women having endometriosis includes both cisgender women and transgender men assigned female at birth. This statistic highlights the necessity for a more inclusive comprehension of endometriosis and how it impacts diverse gender identities. In this thesis, I may use terms like 'women' or 'menstruators' to refer to individuals with endometriosis, acknowledging the limitations of available language in capturing gender identity diversity within this context.

⁵ Endo warrior is a self-referential term embraced by many individuals living with endometriosis. While I personally identify with the term, I acknowledge and honour the diverse perspectives within critical disability studies concerning the use of war metaphors and rhetoric. Given the potential implications and nuances surrounding such language, readers are encouraged to explore literature on related topics, including works by Kristin Garrison (2007), Per Krogh Hansen (2018), and Susan Sontag (1978), for deeper insights.

Despite its high prevalence, for a myriad of both clinical and socio-cultural reasons, the disease recognition of endometriosis remains inadequate and the diagnosis takes on average 7-11 years, with 65% of women being initially misdiagnosed (Greene et al. 2009; Nnoaham et al. 2011). Furthermore, before diagnosis, 63% were told nothing was wrong and their pain experiences were unremarkable (Greene et al. 2009). Without a solid understanding of the underlying mechanisms of the disease, the discovery of a cure is near impossible, hence its characterisation as chronic. Likewise, the treatment options remain inefficient, inadequate, and fundamentally under-researched such that even the management of the symptoms is challenging. Time and time again, when it comes to the symptoms of endometriosis, doctors seem to prescribe some sort of combination of hormonal, pharmaceutical, or opioid/analgesic medication for the individual symptoms long before addressing the multi-systemic disease itself. For example, when patients attempt to communicate their severe pain or other above noted symptoms to medical practitioners, they are largely met with an automatic response of halting menstruation through oral contraceptive (hormonal, IUD, and other forms) combined with the continuous dosing of non-steroidal anti-inflammatory drugs (NSAIDs) (Taylor et al. 2021). When this combination fails, which it does in a third of patients ‘as a result of progesterone resistance or intolerable side-effects...’ (Jensen et al. 2018) the doctor prescribes the second line of treatment therapy which is usually still some combination of oral contraceptive, NSAIDs, and additional pharmaceuticals namely gonadotropin-releasing hormone analogues with progestin, or aromatase inhibitor with progestin, androgen analogues (Taylor et al. 2021). When the medical practitioner accepts the first two therapeutic approaches have not impacted the disease’s spread and pain, the third line of therapy, surgery, is finally introduced and acts as both a diagnostic tool as well as a therapeutic measure.

Approximately 50% of women with endometriosis have recurrent symptoms over a period of five years, irrespective of the treatment approach (Becker et al. 2017). The varied treatment approaches and repeated surgeries not only involve physical repercussions (in the form of increased scar tissue or inflammation, for example), but significantly, catapult a wide array of social, emotional, financial, and professional consequences. Despite all that remains unknown about the disease, in general, it is abundantly clear that the hallmark of the disease is, in one way or another, a multidimensional experience of pain. The chronic and unpredictable nature of the disease contributes to a deep sense of insecurity, shame, and uncertainty in the lives of sufferers (see the reviews by Culley et al. 2013; Gambadauro et al. 2019; Laganà et al. 2017; Pope et al. 2015). As I have personally experienced like so many others, endometriosis is an unrelenting burden of pain and frustration. Navigating a road to relief is not easy nor straightforward.

Though the disease itself is chronic, endometriosis pain may present cyclically, chronically, and/or acutely. Many bodies with endometriosis cycle between immobilised, recovering, and able-bodied. Some months are worse than others. Some years are worse than others with extended interruptions due to surgery or recovery. Indeed this embodied sense of pain’s disruption common in endometriosis is shared and recognisable for many menstruators. For example, studies report anywhere from 16% to

nearly 85% of menstruators experience menstrual pain (Grandi et al. 2012: 170; Ju, Jones, and Mishra 2014: 105) and those who experience menstrual or endometriosis pain ‘lose out when it comes to productivity and income due to pain-based interruptions of work’ (Przybylo & Fahs 2018: 219). In fact, FDS scholar Cara E. Jones notes that individuals with endometriosis in particular ‘lose’ ten hours of productivity per week as determined by more traditional definitions of achievement (2016: 555). The cyclical and long-term pain during menstruation or in some cases, also during ovulation, becomes a relatable and shared experience of ‘familiar and unfamiliar, expected and unexpected, shifting our sense of time’ (Przybylo & Fahs 2018: 219). Considering the high number of individuals experiencing menstrual pain and the severity of endometriosis pain, it would seem logical to offer new productivity and work paradigms for bodies experiencing the cyclic chronicity of this kind of disruption. Several countries have indeed made space for these differences and instituted affordances for menstruating bodies, for example, Japan, Indonesia, Taiwan, and South Korea offer menstrual leave or extra pay when leave is not taken (Matchar 2014). However, the majority of contemporary Western society fails to contend with the turbulent realities of menstrual or endometriosis pain. Perhaps this profound failure originates at least partially in the way pain, more generally, is so easily misconstrued.

Contexts for Understanding, Communicating, or Dismissing Pain & Endometriosis

Embarking on the journey of pain and endometriosis expression entails traversing diverse landscapes of knowledge and perception, each shaping pain’s representation and comprehension in unique ways. The exploration begins within the medical domain, where pain often becomes reduced to clinical metrics, devoid of the intricate nuances of lived experience. Here, the subjective accounts of sufferers are overshadowed by objective measurements and standardised protocols, leading to a dismissal of the depth and complexity of women’s felt experiences of pain.

However, the discussion extends beyond these confines into the expansive realms of humanities and critical theory. Within these contexts, pain transcends mere physical sensations, becoming a subject of ardent inquiry and discourse. In the rich tapestry of narrative medicine, the body's story takes centre stage, offering profound insights into the lived experiences of pain. Moreover, feminist theory discourse and FDS provide invaluable frameworks for understanding the gendered dimensions of pain and the systemic biases that often render it invisible or trivialised — even within the field’s own scholarship.

At the opposite end of the continuum, the arts and arts-based contexts emerge as a powerful realm for articulating the multifaceted dimensions of pain and endometriosis. Here, the body's pain is not just acknowledged, but honoured. In particular, the niche field of painscapes provides a nuanced framework for exploring endo experiences in a robust, interdisciplinary manner without being reliant on language or other barriers that might impede the body’s uninhibited expression of its pain narrative and experience. Navigating these diverse contexts, a spectrum of representations and communication strategies surrounding pain, from its dismissals to more profound and personal engagements is

introduced. By the end of this overview though, an inspired pathway for endo pain to be explored, seen, felt, and heard — becomes illuminated.

The Medical Context

Renowned pain scholar David B. Morris (1991) writes in *The Culture of Pain*, a seminal socio-cultural work on understanding pain, ‘Today, our [Western] culture has willingly, almost gratefully, handed over to medicine the job of explaining pain’ (Morris 1991: 19). The statement, though written a few decades past, still rings true in the present day. Our psychological and biological understanding of pain’s mechanisms continue to expand rapidly. Pain research in the context of medicine, which encompasses fields like medical sociology, medical ethics, healthcare, and psychology, is vast and growing. Entire disciplines within medicine are dedicated to researching the anatomy, physiology, pharmacology, and alternative treatments of pain (Marchand 2012). Indeed, the distinct goal and intention of such fields is to prioritise the treating, the healing, and/or the comforting of those suffering and in pain. Pain has been scrutinised and explored in medicine in depth by researchers like psychologist Dr. Ronald Melzack who together with physiologist Dr. Patrick Wall developed the *gate control theory of pain*, essentially establishing modern Pain Studies (Melzack & Wall 1988). Up until his death in 2019, Melzack was at the forefront of understanding the science of pain and at the helm of developing pain measurement scales like the widely used McGill Pain Questionnaire (Melzack & Katz 2013). Modern medical pain research trends seem to follow the patterns of acclaimed neurophysiologist Dr. Serge Marchand in focusing on physiological, neurophysiological, and psychological aspects of the mechanisms and treatment of pain (Marchand 2012). Indeed, the majority of pain research in medical related fields is concerned with understanding pain from the inside out and fixated on objective measurements of pain that lead to specific characteristics of a diagnosis.

In many medical interactions, the burden remains on the patient to express their pain such that the doctor or other healthcare practitioner unambiguously comprehends the pain. The communication of pain enables healthcare teams to effectively address its underlying origins and subsequently, provide the proper response. It is undeniable then, that language must, to some extent, play a role in establishing dimensions of pain, particularly in clinical contexts (Crawford 2009). However, existing research methodologies and methods in the medical, social, and health sciences, exploring pain experiences and the meaning of pain, have heavily relied upon numeric representations or questionnaires which produce specific kinds of discussions and representations of pain (Miczo 2003; Smith 2008).

For example, in medical settings and research, pain intensity is often measured with numerical scaling from 0-10 or 0-100. Patients tend to rate their pain in relation to function and mobility rather than assessing or expressing internal states, for example (Williams et al. 2000). The format of questionnaires with either numeric scales or pre-determined pain descriptors or characteristics may enable the communication of some pain narratives while effectively stifling others. The wide range of

patient responses often reflects the inherent and complex subjectivity involved with interpreting a pain experience.

Similarly, in sociological or psychological research, interview formats are also implemented to understand pain (Osborn & Rodham 2010). Reviews of pain research interviews frequently document the difficulties of verbalising pain, revealing tendencies and overarching concerns associated with various types of suffering. Although helpful in revealing some insights into pain experiences through the patient's own perspective, they can also be considered limiting in that they also produce, or effectively restrict certain versions of pain. Additionally confabulating, is the tendency of those interviewed about pain to often focus on binaries associated with their experience rather than attempting to reflect on and communicate the multidimensionality of their lived-body experience. For example, chronic pain sufferers highlight feelings of shame or legitimacy related to whether their pain is believed or understood by clinicians, friends, and/or family (Kenny 2004; Toye et al. 2013). Beyond this real/unreal binary, which is a common pain articulation in pain research, a series of other related binaries emerge from interview formats including the invisibility (vs. visibility) of pain; pain being biogenic (vs. psychogenic); and the expert's (vs. patient's) knowledge. Such binaries offer specific versions of pain which often influence how pain and pain experiences are discussed in academic, clinical, and public discourse (Morris 1991).

The dominance of medical and psychological models of pain has led to a neglect of individual experience and subjectivity, 'which in turn leads to a limited approach towards sufferers and a neglect of broader cultural and sociological components of pain' (Bendelow & Williams 1995; Tarr et al. 2018: 578). With such pain communication formats, of course, the gendered components of pain are also systematically overlooked. For instance, most medical literature offers a narrow view of endometriosis and downplays the actual experience of the pain which is often described as 'disabling' (Denny et al. 2011: 168), 'debilitating' (Morris 2006: 9), and 'crippling' (Older 1985: 137) by those who are affected by it (Jones 2016). In relation to physical pain, health policies and systems perpetuate focus on overt and explicit diagnoses of a mechanised body or pain expressed by arbitrary numerical values rather than attempting to attend to the diverse portraits of a human being suffering.

Ultimately, communicating pain remains fraught with misunderstandings and limitations, especially in patient-doctor interactions (Kenny 2004). In many cases, an intense and individual experience such as pain cannot be reduced or codified for universal dissemination. Our inadequacies in expressing the felt-experience of pain to others using words or language sets up a lack of shareability and therefore, to some extent, a dearth of meaningful dialogues around its multidimensionality. This vicious crisis of pain expression effectively leads to misunderstanding, misdiagnosis, and misconception in diseases like endometriosis. Advocacy, awareness, and treatment for numerous painful diseases frequently prove inadequate, resulting in significant patient distress. Physical suffering, emotional anguish, and the entrapment of individuals in the chaos of illness and pain are pervasive. This compels me to question whether I, too, was a patient failed by an unimaginative and perfunctory medical system. I

was expected, and therefore obligated, to articulate the profound aspects of my bodily pain through numerical scales and a limited vocabulary. Inevitably, my attempts to communicate my pain were insufficient, consistently failing to convey the true depth of my suffering.

Humanities & Critical Theory Contexts

The study of pain is far more than a medical problem. Indeed, individual lived-body experiences of pain and the representation of pain are also influenced and shaped by a myriad of influences including powerful cultural forces like gender, religion, race, and social class (Morris 1991: 20; Melzack & Katz 2013; Osborn & Rodham 2010). For instance, health sociology scholar Elaine Denny and her colleagues (2011) note that ‘the experience of endometriosis is bound up with cultural representations of menstruation’ (Denny et al. 2011: 168). Labelling the experience in such terms enables medical practitioners to also then label the severe pain that patients have around the time of their period as ‘dysmenorrhea’ which they categorise as a ‘normal’ part of the menstrual cycle (Denny et al. 2011: 168). There is a pervasive and general ‘acceptance that debilitating pain like menstrual pain is quite the normal routine of any woman’s life’ (Morris 2006: 9). So not only does the medical community often downplay or entirely dismiss the lived experiences of women in pain, but also, due to the nature of deeply ingrained gender norms around female pain and menstrual pain, friends, family, and the public may feel like unreliable support systems. This illustrates why various disciplines within the social sciences, cultural studies, and humanities attempt to produce new knowledge and understandings of pain by considering the experience of pain as related to social systems of power and ecologies of culture. Studying pain in non-medical contexts means thinking differently about and constructing new perceptions of the pain sufferer’s relationship to the world (Frank 1995, 2004). In contemporary experiences of disease and/or disability, those who endure illness or chronic pain are seeking to reclaim their voice and their lived-body experience beyond a medical chart (Frank 1995).

For instance, the fields of medical humanities/narrative medicine and FDS endeavour to understand, express and embrace the lived experiences of people whose bodies are visibly or invisibly ‘different’ from a ‘healthy’, ‘normal’, or ‘able’ body. They each have established histories of and show further promise in cultivating space for sharing stories and perspectives of pain, illness, and healing for a wide range of diverse bodies. Albeit, there are definite gaps, shortcomings, and limitations that need to be addressed especially in connection to female and gendered pain experiences as well as the prevailing reliance on language in pain expression. But at the very least, they have begun to widen and reconsider the ways and forms in which we can communicate and honour our illness and pain stories not just about the body, but through the body.

Narrative Medicine: The Body’s Story

Traditionally speaking, in the social sciences and humanities, pain research has been predominantly analysed through a narrative paradigm (Gonzalez-Polledo & Tarr 2016). Reflective of this, narrative medicine is a field in the medical humanities that emphasises the importance of storytelling and

narrative in healthcare. Narrative medicine was conceptualised as a distinct field by physician, educator, and writer Rita Charon (2001, 2005, 2006) as a transformative approach to clinical practice, enriching it with empathy and patient-centred care. At its core, narrative medicine acknowledges the profound intertwining of illness and healing with personal narratives, advocating for healthcare professionals to attune to and interpret patients' stories with keen ears and open hearts. Through this narrative lens, healthcare becomes more than a clinical and medicalised encounter; it becomes a deeply human exchange, fostering connection, understanding, and healing. While Charon is credited with its origin, narrative medicine and its sub-field of 'illness narratives' builds upon the foundational and theoretical work of Arthur Kleinman, Arthur Frank, and other scholars such as Byron Good, Howard Brody, and Trisha Greenhalgh, who significantly contributed to the understanding and importance of storytelling in medical practice (Good 1994; Brody 2003; Greenhalgh 2001).

'Illness narratives' in particular emerged as a vital conduit for understanding and articulating the lived experience of illness and pain, diverging from the mechanised expressions commonly found within medical and healthcare contexts (Kleinman 1988). Within this unique niche, the body⁶ is given a voice through storytelling. Stories are told not just about, but through, wounded bodies. There is, as of yet, not a pain narrative speciality in this field, per se, but often these stories of illness have pain at their very core. Unlike traditional healthcare approaches, the study and practice of illness narratives prioritise the voices and experiences of patients and sufferers rather than healthcare practitioners, and in doing so, amplify the body's story (Charon 2006; Kleinman 1988). Much of illness narrative literature, both the personal storytelling manifestations and the critical analysis of such, offer poignant insights into the human experience amidst acute illness, chronic illness, or disabilities (Charon 2005: 30). Hurwitz, Greenhalgh and Skultans (2004) define illness narratives as 'polymorphous, malleable and dynamic devices' through which pain and disease are appreciated and communicated in clinical contexts and beyond (Hurwitz et al. 2004: 2). What counts as an illness story is not necessarily clear as these narratives may be communicated with different tones, arcs, and intentions. However, in the broader scope of narrative medicine, the accepted tradition and paradigm seems to be that the story is told either through written or spoken words (Kleinman 1995; Frank 1995). Sometimes illness narratives are co-authored by patients and doctors in the clinical process of understanding the context and prognosis of a particular disease or pain (Kleinman 1995). In other cases, the patient's story might be told through another person's point of view in order for the communication to be cohesive and shareable. Often the approach to telling an illness story draws on structural and sociolinguistic approaches in narrative theory which can be both restrictive and prescriptive for the storyteller themselves. These narratives, frequently raw and expressive, serve as vehicles for transcending conventional modes of pain communication, which make them of particular interest to this project.

⁶ Throughout this thesis, I refer to the 'body' repeatedly. In most cases, I am actually referring to the body with reference to Margaret Price's 'bodymind' or Arthur Kleinman's 'body-self', both of which acknowledge the body's inseparable connection to the mind as well as the emotional, the psychological, and the spiritual aspects of self. (Kleinman 1988; Price 2015)

Esteemed medical sociologist and philosopher Arthur Frank discusses the importance, function, and types of illness narratives in his influential book *The Wounded Storyteller* (1995). After personally suffering illnesses that changed his life, his writing passionately presents profound theory and scholarship with discerning insider insight and sensitivity. Essentially, illness narratives, whether published, unpublished, formally documented, or colloquially shared, are the stories of an ill person's lived-body experience (Frank 1995). These embodied stories transcend a doctor's medical chart, a list of symptoms, and a diagnosis. Rather, an illness narrative attempts to candidly reveal how a disease has impacted and indeed transformed a body, mind, and soul. Illness narratives are considered central forms of communication through which people in pain make sense of the complexity of the illness experience and carve out space for healing (Kleinman 1988, 1995).

According to Frank, illness narratives can be categorised as restitution, quest, and chaos narratives. Restitution and quest narratives are the culturally preferred journey for both experiencing and witnessing illness. Such narratives employ a more standard narrative structure and arc and ultimately, represent hope and resilience. In a restitution plot, the ill body returns to a pre-illness status quo state and the body is restored. Similarly, in the quest narrative, an individual accepts and comes to embrace past suffering as an inspirational, heroic, and purposeful lesson. Despite the complex transformation depicted in the quest narrative, these stories are typically associated with successful treatment or survival. In both of these styles of illness narratives, the focus is on emerging from the illness experience either cured and well or changed and stronger than before. Consequently, such narratives are less representative of chronic illness which usually corresponds to incurability and entails a journey that does not lead to a return to 'normalcy' but rather involves ongoing adaptation and management.

On the contrary, a chaos illness experience is an *anti*-narrative, one that defies writing or telling. Chaos narratives are always on the borders of language because where life can be given narrative order, chaos is already at bay (Frank 1995). Chaos is:

...the hole in the narrative that cannot be filled in, or to use Lacan's metaphor, cannot be sutured. The story traces the edges of a wound that can only be told around. Words suggest its rawness, but the wound is so much of the body, its insults, agonies and losses, that words necessarily fail... (Frank 1995: 98).

In his writing on chaos narratives, Frank exemplifies the chaotic experiences of an endometriosis patient, Sally Golby, who felt 'emotionally battered' by her doctors in her struggle to gain recognition of the disease (Frank 1995: 101). Experiences like chronic pain or endometriosis often fall outside the ability of narrative to adequately account for them. Reflective space is often required for some semblance of communication to be realised and for those in unrelenting pain, that reflection is often denied.

The power of the illness narrative lies in the storyteller and a listener or an empathetic witness as Kleinman (1995) proposes — and the relationship between them. When a story of pain or suffering is expressed and communicated, the storyteller gives voice to her body and works through the identity changes that have emerged as a result of the illness or pain journey. Audre Lorde, celebrated poet and feminist writer who found herself in the space of illness narrative as the result of breast cancer, indicated that writing about her illness experience helped her ‘reclaim herself and her body’ (Frank 1995: 64; Lorde 1980). The story becomes a living testimony of and through the body.

Part of what makes an illness story a true testimony is a call upon others/witnesses to receive them (DasGupta & Hurst 2007: 20). As Frank so eloquently states, ‘The communicative body needs the other in order to commune...’ (Frank 1995: 144). Bearing the reclaiming and reconstruction of a person’s life during and/or after illness empowers the teller and sufferer, but also, provides guidance to those who may follow and helps caregivers appreciate the illness experience more fully. In a sense, through the act of storytelling, the sufferer hopes to bring presence and value to her voice, body, and experiences by affecting the lives of others. Perhaps, through communicating their lived-body experiences, those suffering in illness and/or pain hope to find meaning and transformation by impacting and connecting with others.

Although the various modes of storytelling in illness narratives often derive functionality from their analytical use in clinical and caring relations (Frank 1995; Bury 2001), they often fall short in their attempts to adequately communicate the intricate, layered, and multiple temporal, social, psychological, physical, and emotional dimensions of pain. Arguably, by perpetuating traditional formats of storytelling, they ultimately prioritise the patriarchal traditions embedded within the field of medicine rather than challenging existing social, cultural, and political hierarchies. This is especially true in the ways in which pain and female pain experiences are expected to be communicated (or not communicated) within existing humanities, social sciences, and medical literature. Perhaps, the chaos experience in particular needs to be expressed and shared through alternative modes of communication that push against traditional storytelling methods and forms. I believe this is where artistic expression and the experience of pain/the communication of pain might serve as an especially prized intersectional space for those living in the chaos of a chronic illness or pain experience and an effective means of communicating these experiences. As touched on below and in more depth in Chapter 2, the chaotic experiences of interruption, disruption, and disorientation associated with incurable pain, disability, or disease are what this research explores. Ultimately this is achieved by experimenting with alternative, nonverbal forms of narrative and unconventional perspectives of time and space in artistic research and art-making.

Feminist Theory Discourse and Feminist Disability Studies (FDS) Contexts

Because endometriosis is intrinsically linked to gender due to its intimate association with menstruation and its impact on fertility (Jones 2016; Shafrir et al. 2018), feminist/FDS thinking serves as a critical umbrella not only philosophically illuminating, but also driving the research

methodology. Specifically, feminist theory has a distinct interest in women's lived-body experiences while FDS probes critically around women's illness experiences. Much of the feminist scholarship I hone in on focuses on the analysis of patriarchal structures and sociocultural systems that impact gender identity, women's health issues, and embodiment. Over and over I ask: where are the discussions around the systemic downplay of female pain and then, how might we express our pain stories, as chaotic as they may be, in ways that will be heard and valued. In response, this project ultimately contributes to expanding ongoing discourse in these fields.

I begin briefly with pioneering work from feminist scholars Iris M. Young and Simone de Beauvoir in order to then launch more critically into theory from theorists Sara Ahmed and Lisa Baraitser (discussed in depth in Chapter 2). Later in the thesis, more seminal feminist thinking is referenced, from Julia Kristeva and Barbara Creed (Chapter 6) as are the writings and practices of contemporary queer dance artist Emilyn Claid (Chapters 3 and 6). Likewise, I further establish my feminist perspective and voice using the powerful writings and urgings of key feminist disability scholars like Rosemarie Garland-Thomson, Susan Wendell, and Alyson Patsavas. Most specifically, as discussed in detail in Chapter 2, this research engages with FDS theory from Alison Kafer as well as dance artists Ann Albright Cooper and Sarah Whatley. Collectively, these feminists provide inspiration and imperative in order to 'think and talk more carefully about pain — not in order to overcome it, but in order to overcome the many oppressions that attempt to annihilate us for feeling pain...' (Patsavas 2014: 204).

For instance, Iris M. Young and Simone de Beauvoir have indeed established foundational discourses and theorising around female embodiment, the phenomenological experiences of pregnancy and menstruation, and the lived-body experiences of womanhood in general. However, there is no substantive consideration of female pain experiences in feminist and feminist phenomenological literature.

In her essay collection: *On Female Body Experience* (2005) which shares various phenomenologically driven essays about female embodiment, Young also acknowledges:

Oddly, feminist scholars have thought systematically very little about these ordinary body experiences with which most women identify specifically as women, even though the concrete quality of these experiences vary greatly (Young 2005: 6).

Young claims one of the purposes of this collection is simply expressive, 'to give words to meanings often unspoken' (Young 2005: 3). Yet this celebrated collection of essays which reflects on several aspects of women's everyday lived-body experiences, only briefly mentions discomfort in the context of menstruation and labour/childbirth without any dedicated, in depth discussion (Young 2005). Her philosophical elaborations, similar to Beauvoir and other feminist philosophers, are heavily slanted towards the situation of the female body in relation to social norms rather than female physiology and anatomy in conjunction to sociocultural contexts (Young 2005: 29). I concur with Young that it is odd

that feminist scholars still systematically neglect the everyday experiences of women (for example, bodily comportment in sports activities; inhibited intentionality; menstruation and shame; pregnancy; and the experience of having breasts).

As a reference, Sara Ahmed, writes an entire chapter about pain in her book *The Cultural Politics of Emotions* (2014) called, 'The Contingency of Pain' which I have previously referenced in this chapter. At some points throughout the robust analysis and theory around pain, she even briefly shares and describes her own experiences of pain in the context of menstruation:

In my experiences of period pain, for example, I feel a dull throbbing that makes me curl up. I try to become as small as possible. I hug myself. I turn this way and that. The pain presses against me. My body takes a different shape as it tries to move away from the pain... (Ahmed 2014: 26).

However, not spending more than a few sentences on the topic, Ahmed significantly writes about the noticeable absence of dysmenorrhea (a symptom of endometriosis) from feminist phenomenology and existentialism in her footnotes section:

Period pain is not a pain that has been written about within the context of existentialism or phenomenology, even by feminists working in these traditions. Yet many women suffer from period pain in a way that affects what they can do with their lives. It is important to write the lived experience of period pain into our theorising of embodiment. The discomfort we might feel in writing such pain into a philosophical body is like many discomforts: it is caused by not quite fitting the body (in this case, the philosophical body) we inhabit (Ahmed 2014: 40).

After analysing these above works, the closely related writings of Beauvoir in *The Second Sex* (first printed in 1949); and other feminist texts (Bloodsworth-Lugo 2007; Conboy, Medina & Stanbury 1997; Price & Shildrick 1999), it becomes evident that female pain experiences remain largely absent or assigned to footnotes in feminist works. This indicates an obvious need to study such experiences of female pain like endometriosis more critically and moreover, reveals why FDS might be a vital field to pinpoint in contextualising and expanding endometriosis research and discourse.

The goal of FDS has always been to undertake a 'deeper critique that problematises and politicises ideological concepts such as health, disease, normalcy, cure, and treatment' (Garland-Thomson 2005: 1560). FDS scholar Susan Wendell urges disability educators and researchers to understand chronic illnesses/diseases as disabilities (Wendell 2001:17). Likewise, she contends that because women endure and encounter chronic illness conditions more often than men, 'any adequate feminist understanding of disability must encompass chronic illness' (Wendell, 2001: 18). For example, FDS scholars have drawn attention to and attempted to offer analysis around conditions that women commonly experience such as lupus, breast cancer, migraine headaches, MS, rheumatoid arthritis, fibromyalgia, and depression (Wendell 2001: 25). Despite its gendered nature and chronicity,

women's experiences of endometriosis and other gendered disabilities⁷ are still often not analysed or theorised about in FDS discourses even though other conditions which cause pain have been, like those mentioned above.

The exclusion of endo might relate to an intimate reflection on 'dissonant disabilities' offered by disability poet and scholar Emilia Nielsen (2016). In an article discussing her personal experience of an auto-immune disorder, Nielsen expresses feeling excluded from disability culture due to the illness' invisibility despite experiencing both physical and cognitive impairments. She writes: 'I felt written out of disability culture because I did not see my experience reflected in the images and words with which I was engaging' (2016: paragraph 8). Discovering the concept of 'dissonant disabilities' reinforced her belief in the importance of studying chronic illness within disability frameworks and emphasising the lived experience of ongoing pain and fatigue (Nielsen 2016: paragraph 8).

The term 'dissonant disability', introduced by disability scholars Diane Driedger and Michelle Owen (2008), refers to the lack of harmony or alignment between an individual's experience of chronic illness and societal perceptions or expectations of disability. 'Dissonant' implies that, unlike more visible or traditionally recognised disabilities, chronic illnesses and chronic pain may not always be readily apparent to others. As a result, individuals with chronic illnesses or pain face unique challenges in having their experiences validated or understood within the broader disability framework. This disconnect arises because pain and illness, being often invisible and subjective, are marginalised or dismissed within traditional disability discourse, which typically emphasises more visible or quantifiable impairments. This term highlights the discord between the internalised experience of chronic illness and pain and the external perceptions of disability within society. Consequently, individuals with chronic pain or disease may struggle to have their experiences validated or accommodated within disability frameworks. This highlights the need for a more inclusive and nuanced understanding of disability that acknowledges these experiences.

Nielsen's (2016) writing encapsulates the dissonant nature of both chronic illness and pain, emphasising their perpetual disruption and the simultaneous coexistence of wellness and sickness. As in the case of endometriosis, dissonant disabilities challenge conventional biomedical paradigms that predominantly address acute conditions. Nielsen posits that scholarship from dissonantly disabled individuals possesses a dual capacity: it uncovers often obscured realities and produces work that mirrors the disruptive, unpredictable, and unruly nature inherent in the bodies and minds from which it emerged.

⁷ In a recent article, FDS scholar Cara Jones argues for the term 'gendered disability' when discussing diseases like endometriosis. She defines gendered disabilities broadly, including chronic illnesses that involve the uterus, ovaries, and other body parts traditionally classified as 'female'. I use gendered disability or gendered pain interchangeably when reference endometriosis and related diseases (Jones 2020). In general when I write about endometriosis throughout this thesis I am also acknowledging conditions like adenomyosis or PCOS to name a few.

In a similar vein, Cara E. Jones repeatedly points out that ‘FDS must meaningfully engage with the lived reality of pain as well as its representation’ (Jones 2016: 4). This emphasis on recognising and interrogating the lived reality of pain resonates with ongoing discussions within FDS about the need for inclusive analyses of chronic conditions. It particularly aligns with Alyson Patsavas’ concept of ‘cripistemology of pain’ (2014). The term cripistemology is derived from the word ‘crip’ which is a reclaimed term used by some disability activists and scholars to describe themselves and their experiences (crip identity is elaborated upon in Chapter 2). Epistemology refers to the study of knowledge and how it is acquired, which is why ‘cripistemology’ specifically focuses on how disability is understood and experienced within different knowledge systems and social contexts. Consequently, Patsavas’ cripistemology of pain refers to an approach to understanding pain that takes into account the experiences of people with disabilities. She challenges ableist attitudes toward pain and disability, advocating for a more precise understanding that recognises the diverse experiences and perspectives of individuals living with chronic pain and illness. Through her work, Patsavas seeks to illuminate the intersections between pain and disability, offering critical insights into the complex relationship between embodiment, identity, and health. Through her work, Patsavas clearly links pain with ‘crip’ identity in the context of FDS. Relatedly, pushing for a feminist disability theorising of endometriosis, Jones (2016) writes, ‘endo discourses are a necessary site of intervention for feminist disability inquiry into pain’ (5).

This research gains traction by mobilising the insights stemming from endo, female pain, and other gendered disabilities’ exclusion in feminist and FDS scholarship. Viewing endo as a site of intervention, as this research does, provides a clear entry into an in-depth, long overdue feminist disability inquiry around pain exploring the intricate dynamics surrounding the expression or repression of disorderly bodies like mine and others. As will be outlined in Chapter 2, applying feminist and disability/crip vantage points to time, space, and corporeality in and through art-making, I discovered the latent potential nestled within the more dissonant attributes associated with endometriosis. These same characteristics, embodiments, and experiences — namely, disruption, disorientation, incurability, chronicity, or invisibility — transformed into potent points for creative rupture. This transformation begins and ends with pain, shaping both the inception and conclusion of this research journey.

Arts & Arts-Based Contexts

Words and verbal language, constrained by conventional communication and narrative paradigms (i.e., interviews, medical charts, symptomatology, questionnaires, pre-articulated measurements, numbers, and critical writing), are the typical formats relied upon in the previously discussed fields. However, pain communication has also been explored through other forms of expression. Reviewing the study of pain across more creative fields reveals artists and researchers using different mediums and modalities to explore the communication of pain and/or disability experiences without relying solely on words or adhering to traditional linguistic patterns and standard communication formats.

Particularly, considering the limitations and gaps resulting from the earlier stated contexts, developing pain testimonies that transcend verbal language and invite multidisciplinary expands the understanding of otherwise inconceivable experiences. Additionally, as previously discussed in this chapter, aligning with pain scholars such as Joanna Bourke, creative endeavours that articulate pain might be instrumental in eliciting new language to describe pain phenomena and experiences. Studying pain outside of medicine or the humanities and instead through the arts may help transform the space of suffering and provide new possibilities for understanding the evolving body, mind, voice, and identity in response to pain.

Deepening my knowledge of these perpetually evolving domains influenced the development of this research's methodological considerations and artistic practices. Given my own background and expertise in the performing arts, I became more drawn to these creative explorations of pain and the lived-body experiences of pain, disease, or disability. What new insights and knowledge might we unearth by exploring the communication and expression of female pain, such as endometriosis pain, beyond the more typically accepted linguistic and numeric forms? Can unconventional modalities of communicating and expressing pain catalyse new dialogues and lend greater weight to the experiences of women in pain? How can verbal and nonverbal expressions complement each other in the divulgence of pain experiences? In considering these questions, I became interested in researching at the edges of or beyond the traditional parameters of pain research in relation to this project's purpose and aims.

Of course, the worlds of art, pain, and expression have always been inextricably linked. Historically, a myriad of artists have channelled their personal pain into art and incorporated their experience of pain into an artistic identity. Over time and according to sociocultural sensibilities, taboos, or aesthetics, the representations, modalities, and expressions of pain have evolved, ebbed, and flowed. As individual artists' sources of pain or relationship with pain differ, so too do the artistic ways in which pain is engaged with as material, content, or inspiration. The multidimensional ways pain has been inventively manipulated, explored, activated, and expressed by artists over time is fascinating, yet indeed, the breadth of this topic remains too wide for this dissertation alone. However, before moving to contemporary artistic practices of pain expression, it is important to acknowledge a few influential artists who have directly incorporated pain in their creative practice in order to exemplify the established link between art and pain.

Habitually, the art-history canon reveals many professionally thriving artists living with emotional and/or psychological pain who engage in art-making as a form of catharsis. Celebrated artists like Edvard Munch or Vincent Van Gogh, who openly suffered from mental illness and who undoubtedly experienced tumultuous anguish from inner pain, may only have been capable of expressing themselves through their artistic medium. Other more seminal artists in the pain art canon, which are of foundational pertinence to this research, include Bob Flanagan (American performance and BDSM artist); Marina Abramović (Serbian performance artist); and Frida Kahlo (iconic Mexican painter).

These artists have provocatively, overtly and intentionally used their bodies and lived experiences in their artistic practices and publicly exhibited artworks. Whether the pain's origin is from an illness or disease, inflicted with intention onto their own bodies, or is the result of trauma, exploring pain and communicating pain in creative ways can be extremely powerful.

For instance, Flanagan incorporated both performative sadomasochistic practices and went to great lengths to visibly expose his audience to the medical paraphernalia and settings (oxygen tubes, hospital beds, anatomy theatres) required for his body to function with cystic fibrosis while engaged in performance rituals. As disability scholar and artist Petra Kuppers discusses in her book *The Scars of Visibility* (2007), 'Flanagan's performance disrupts conventional codes of sentimentality' as he played with his body's experience of chronic pain while exercising his artistic agency involved (79). He allowed spectators to observe the infliction of extreme pain on his physically vulnerable and visibly different body (Kuppers 2007). Flanagan's strategy of communicating pain elicits nuanced responses and awareness from the audience as they consider and reconsider a disabled body experiencing pain. Indeed, his use of pain and body in his artistic practice challenges the audience to evaluate their own relationship to their body and pain.

Similarly, to note a few of Abramović's intense performance acts: she combed her hair until her head bled; laid down on ice blocks; stabbed herself repeatedly; and ran into cement pillars (Abramović 2016). Pain is an obvious and recurrent theme in Abramović's endurance art practice. She conditions her body to experience, suffer, or endure pain or extreme discomfort over periods of time. Also, related to some of the underlying curiosities of this research, she explores how inviting pain into creative practice particularly within the context of live audiences creates opportunities for dialogues and alternative understandings around the body, mind, embodiment, transcendence, and transformation (Abramović 2016). Although she may not have chronic pain herself, the art is touching on the experience of physical pain and stamina.

Kahlo's personal suffering and artistic voice are inseparable; indeed the first birthed the latter. After the infamous bus crash in which her body was nearly severed in half by a rod that exited through her pelvic floor, teenage Kahlo wrote to her lover, 'I wish I could explain to you my suffering minute by minute' (Herrera 1983:40). Immediately following the accident, Kahlo was encased in a full body cast and began her life stranded on what she described as a 'painful planet' having to endure over 30 surgeries and multiple re-hospitalisations (Herrera 1983). Throughout the initial recovery period, she metamorphosed into the unapologetically honest artist she is celebrated as today.

Artistic expression empowered Kahlo to authentically communicate the inherent chaos of her pain story. Likewise, beyond becoming a tool of communication enabling others to bear witness, the artistic process became an intimate form of personal support, reinforcing her voice and story as valid, and nurturing her spirit in a tumultuous journey falling and rising from pain. Kahlo first began by painting the corset-like casts reconstructing her own brokenness into artefacts of pain expression and vulnerable disclosure. Her embrace of painting continued and, as a way to both document and depict

her convalescence and suffering, she turned to evocative and viscerally direct self portraiture. Considered radical for the early twentieth century, Kahlo openly shared her most private and painful experiences including a devastating miscarriage revealed in *Henry Ford Hospital (1932)* where she is seen bleeding as tears slide down her face (<https://www.fridakahlo.org>). Battling chronic pain and visible disability for the entirety of her artistic career, she remains one of the most inspiring precedents of the powerful intersection of art and disability/pain/illness narrative. Undeniably, the force of emotion with which she visually articulates her pain could hardly be conveyed using words.

Notably, apart from Kahlo, women suffering from chronic disease, painful menstruation, infertility or childbirth are almost invisible in the history of art (Sontag 2003). Likewise, contemporary art is still struggling to break this pattern, though there are some important female artists to mention in relation to an expanding disability art canon. For example, Claire Cunningham (UK dance artist); Lisa Bufano (American performance artist); and Heidi Latsky (American dance-based artist) have all used their or their dancers' personal experiences with physical disabilities to create compelling works that challenge and engage audiences. Cunningham's performances, such as *Guide Gods* (2014), use her crutches and her experiences as a disabled individual to explore themes of pain, faith, and societal perceptions of disability (<https://www.clairecunningham.co.uk/>). Bufano's performances, such as *One Breath is an Ocean for a Wooden Heart* (2007), transformed her amputated body into a powerful artistic statement, challenging conventional ideas of beauty and movement (<https://www.lisabufano.com/>). Latsky's *GIMP* (2008) and *On Display* (2015) performances celebrate the unique physicality and expressiveness of disabled dancers, pushing the boundaries of conventional dance aesthetics (<https://heidilatskydance.org/>).

Additionally, menstrual art, a genre that uses menstruation as a central theme or medium, plays a crucial role in challenging societal taboos and celebrating female bodily autonomy (Green-Cole 2020). Pioneering feminist artist Judy Chicago's *The Dinner Party* (1979) uses symbolic imagery to honour historical and mythical women, bringing attention to often marginalised female experiences, including menstruation. Similarly, Vanessa Tiegs' *Menstrala* (<https://www.menstrala.com>) series employs menstrual blood as a medium, transforming a natural bodily function into a source of artistic inspiration. Although these works do not specifically address pain, their contributions to the field in terms of bringing visibility to female experiences and advocating for menstruation related art's inclusion in the broader art history canon.

While my research practice differs from most of these noted artists, I do not deliberately inflict pain on self or others; eroticise pain experiences (like BDSM performance art); create literal representations of a disabled body or body parts; or curate visible spectacles incorporating medicalised routines — it nonetheless shares the common goal of communicating and expressing pain. Despite stylistic and technical differences, this project draws essential insights from these and other artists' explorations of pain, aligning with a broader desire to communicate, express, and research pain through non-medical means.

In this context, over the past two decades in particular, there has been a growing body of research focusing on the use of arts-based approaches to communicate and express experiences of pain. Questions have increasingly arisen surrounding the interplay between pain experience and expression, necessitating ongoing dialogue across the humanities, art, philosophy, and science. Notably, key researchers embracing this approach include Gillian Bendelow, Joanna Bourke, EJ Gonzalez-Polledo, and Jen Tarr. Interestingly, their academic backgrounds span diverse disciplines, from history to anthropology to medical sociology to research methodology, reflecting a wider interdisciplinary effort to understand and communicate pain.

For example, social researchers are increasingly employing the arts to explore and access knowledge which is not easily expressed in words (Tarr, Gonzalez-Polledo, & Cornish 2017). Similarly, and of relevance to this research, arts-based methods are being integrated into health-related research, sometimes directly within healthcare settings and complementary pain therapies for pain management, due to their efficacy in facilitating the expression of experiences that defy verbalisation (Stuckey & Nobel 2010: 256). Moreover, embracing an arts-based approach can generate and disseminate novel forms of knowledge about health-related issues (Fraser & al Sayah 2011). For instance, Bruce et al. (2023) have highlighted the significance of arts-based research in enhancing our understanding of the lived experiences of individuals with chronic pain within healthcare contexts, underscoring the unique insights gained through creative modalities. Additionally, work by Johnson et al. (2023) has delved into the intersection of pain, politics, and artistic representation, illuminating the role of artistic expression in articulating the complexities of pain and its impact on identity and rehabilitation. Furthermore, research by Raudenská et al. (2023) and Lee & Angheluta (2011) have explored the therapeutic potential of expressive therapies for women coping with chronic pain, emphasising the continuum of self-care facilitated by artistic expression. Together, these studies demonstrate the increasing recognition of arts-based approaches as valuable tools for exploring and communicating the multifaceted nature of pain experiences.

A significant example of leveraging an arts-based approach from a social science perspective, which greatly influences this research project, is found in the accumulating body of work initiated by the scholars noted above, EJ Gonzalez-Polledo and Jen Tarr. Gonzalez-Polledo and Tarr are important current figures in the pain studies landscape who use alternative, non-medicalised modes of communication and expression of pain. For example, Gonzalez-Polledo and Tarr worked as co-investigators on the UK project *Communicating Chronic Pain*: a project aimed to explore non-textual methods of communicating about pain (Tarr, Gonzalez-Polledo & Cornish 2017). In this project, the researchers conducted a series of art-making workshops devoted to empowering participants to collectively explore not only art-making practices they may be unfamiliar with, but also, an opportunity to communicate, relate to, and assign meaning to their chronic pain in ways they may not have explored before (Tarr, Gonzalez-Polledo & Cornish 2017). The research design included four arts-based workshops with a heavy focus on visual arts, although there was one session using sound. The workshop participants included not only chronic pain sufferers, but also caretakers and medical

professionals. Though there are several areas to expand upon in the research, it is generally clear from the feedback and discussion that the use of live workshops, but also specifically, art-based and art-making methods, yielded a productive ethos of openness and non-judgment. Such an ethos seemed to allow for discussions of themes that ‘were otherwise difficult to verbalise’ (Tarr, Gonzalez-Polledo, & Cornish 2017: 586). The kind of space cultivated in these particular workshops, through art and art-making, is something I aimed to foster and extend in my exchanges with other women in this research (which will be described in depth in Chapter 4).

Gonzalez-Polledo and Tarr’s work highlights how art-making and artistic methods might communicate ‘multi-sensory and non-verbal dimensions of pain to augment language’ without focusing on the use of participatory arts methods as art therapy per se (Tarr, Gonzalez-Polledo & Cornish 2017: 580). For instance in their chronic pain project cited above, although many workshop participants expressed certain art-making experiences and workshop sessions as transformational, the intention of the workshop and research was not necessarily to be therapeutic ((Tarr, Gonzalez-Polledo & Cornish 2017). These are important distinctions; they also serve as principles guiding my own research design. My intentions and methods distinguish the art-making and creative processes as means to communicate and develop new dialogues about female pain, without a need or expectation to heal the trauma of pain or intend for the pain to be treated or cured.

Gonzalez-Polledo and Tarr’s research endeavours led to them co-editing and contributing writing in the book *Painscapes: Communicating Pain* (2018). This collection of essays from artists, artist researchers and academics who use the arts in their research, demonstrates an emerging field of pain study outside of medicine. This volume combines insights from anthropology, sociology, the medical humanities, and the arts and ‘draws on phenomenological and post-phenomenological approaches to pain communication’ (Gonzalez-Polledo & Tarr 2018: 4). In this intersectional space between pain and communication, ‘the contributors reimagine pain through intersubjective, temporal, material, and knowledge ecologies: painscapes’ (Gonzalez-Polledo & Tarr 2018: 5). As defined in the book’s preface, painscapes:

...aim to provide alternative ways of understanding pain through devices such as images, poems, historical texts, stories, and qualitative modes of understanding which both intersect and diverge, helping us to navigate pain’s complexities... (Gonzalez-Polledo & Tarr 2018: preface).

In this vital curation of painscape research, notably, many of the practices presented in the collection are facilitated by hired artists while principal researchers both observe and partake in the art-making. Researchers like Gonzalez-Polledo, Tarr, and other social scientists enter the arts-based research space from a much different perspective than that of art practitioners, and as a result, the knowledge they pinpoint is influenced by this particular point of view. Despite this however, the individual and collaborative research of Tarr and Gonzalez-Polledo has still managed to garner interesting insights and momentum in the space of both pain studies and art-making processes. In fact, throughout this

thesis, I lean into their coined term of painscapes and conceptualise it as an excellent description of an emerging field as well as methodological framework which sits dynamically in the convergence of pain studies, pain communication, and creative expression/arts research. Likewise and fortunately for artists interested in this developing field of alternative pain communication, their existing research makes room and indeed establishes the need for painscapes research emanating from the point of view of artists like myself. This point led me to choose a painscape artistic research methodology which is discussed in more detail in the forthcoming chapter. This painscapes research project remains similarly still centred around experiences with pain, however, my positioning not as social scientist, but as pain sufferer *and* art maker, paved a much different methodological journey generating novel insights in both pain experiences as well as embodied creative practices rooted in pain. The painscapes space is one to which this research project makes robust contributions (these contributions and the role of painscapes in generating the concept of netherness are clarified more in depth in both the conclusion section of Chapter 6 as well as the Conclusion chapter).

Naturally, some existing painscapes research emanates from contemporary artists who might not explicitly identify their work as ‘painscape research’ yet distinctly utilise pain as a starting point or tool in their creative practice. Many of these practitioners engage in their art without formal academic affiliation or research intentions, resulting in approaches to pain communication and the intentional integration of pain as source material that may not be as thoroughly documented.

Within this realm of painscape artists are several notable female creators who publicly acknowledge suffering from endometriosis, such as Eugenie Lee (Australian interdisciplinary artist; <https://eugenielee.com.au/work>); Solomon (Ellie) Kammer (Australian figurative painter; <http://solomonkammer.com/>); Rachael Jablo (American multimedia artist; <https://www.rjablo.com/hysteria>); and Georgie Wileman (British photographer; <https://www.georgiewileman.com/>). These artists, whose pain experiences resonate deeply with my own, illustrate the profound and nuanced impact of endometriosis on their creative trajectories and artistic outputs. Although comprehensive interviews and analyses of their work fall outside the scope of this thesis, their significant influences on the painscape and endo-centric art realm are recognised. I encourage readers to explore their portfolios for further insights into themes like invisibility and the violence of endometriosis pain. Such exploration will deepen appreciation for the development of an endo-centric painscape field, to which this research adds value.

A small portion of painscape or ‘pain world’ (Meehan 2023) artists are disseminating or writing about their research in academic scholarship contexts. Artists whose research and practices I specifically reference throughout this thesis include Deborah Padfield (interdisciplinary, lens based artist), Petra Kuppers (poet and community performance artist); and Sarah Hopfinger (live artist and choreographer). These three artists have well established practices integrating their artistic practice with academic research/scholarship and personally identify with chronic pain and/or illness

experiences marked by pain. Throughout this dissertation their work will be referenced particularly in relation to the artistic practices produced from this research.

Deborah Padfield is a visual artist specialising in lens-based media and intersectional practice and research within fine art and medicine. She is currently a lecturer (teaching) at the Slade School of Fine Art, UCL (<https://www.ucl.ac.uk/slade/people/academic/dgpad35/>). Padfield's research focuses on the utilisation of images and image-making processes to enhance the diagnosis and management of persistent pain. Padfield contends that photographs play a pivotal role in facilitating improved interaction and mutual understanding among patients and clinicians in pain clinics, as well as between individuals experiencing pain and those observing it. Having collaborated with prominent pain specialists and academics across various disciplines and institutions, Padfield advocates for collaborative approaches in art-making, research, and teaching. Her teaching philosophy is heavily influenced by her research and artistic practice, both of which emphasise bringing together individuals with diverse expertise and talents, with Padfield at the forefront, to foster connections, explore unfamiliar methodologies, and generate new knowledge collectively. Padfield firmly believes in the power of interdisciplinary collaboration to tackle contemporary global health challenges. Additionally, she asserts that the arts serve as a crucial resource for promoting health and well-being, and she hopes for their continued integration into social prescription practices to enrich and enhance lives. Her commitment to externalising and creating visibility for a hidden experience like pain provides core direction for this research.

Another important point of reference over the course of this research journey, is the work of disability culture activist and community performance artist Petra Kupperts. As of 2024, Kupperts is the Anita Gonzalez professor of performance studies and disability culture in the English and Women's & Gender Studies Departments at the University of Michigan, Ann Arbor. According to her website, she creates 'participatory community performance environments that think/feel into public space, tenderness, site-specific art, access and experimentation' (<https://petrakuppertsfiction.wordpress.com/about-petra/>). In both her scholarship and creative work, she employs disability culture methods, and uses eco-somatics, performance, and speculative writing to engage audiences 'toward a more socially just and enjoyable future' (<https://petrakuppertsfiction.wordpress.com/about-petra/>). Kupperts's extensive work in poetry, community performance, and disability/crip culture scholarship compellingly and deeply connects theory with creative explorations. In much of her writing on disability and crip theory, Kupperts underlines the deficits around pain (communication) in crip culture and by extension, its related neglect in queer/feminist/disability discourse (Kupperts 2008: 75). Her work often raises questions of how to celebrate difference and beauty in disabled or chronically ill individuals without diminishing the material challenges and substantial pain it may inflict on that person's body and mind. In attempting to confront some of these questions, Kupperts's focus, like my own, shifts to the relationship to the body, lived experience, and the resulting creative/artistic practices of those who suffer pain. As in this research, the body and creative voice; experiences and

expressions; and verbal and nonverbal languages ebb and flow into and out of one another, exploring and building new worlds.

Comparably in a sphere of disability, queerness, and crip practices, Sarah Hopfinger works across live art forms (performance art, choreography, and theatre) and is a lecturer and researcher in contemporary performance at the Royal Conservatoire of Scotland (<https://www.sarahhopfinger.org.uk/>). Hopfinger honours her own chronic pain and acknowledges other bodies in pain by creating ethical and impactful art that celebrates ‘the rich complexities of living with pain’ (<https://www.sarahhopfinger.org.uk/pain-and-i>). Of great interest to this project, Hopfinger recently received funding to pursue ‘practice-led research that explores, through performance practice and theoretical engagement, connections between human experiences of chronic pain and wider ecological pain’ (<https://www.carnegie-trust.org/alumni/dr-sarah-hopfinger/>). Her unique integration of creative expression, lived-body chronic pain experiences as well as an ethics of care distinguishes her as an important voice in the world of painscapes. Using her artistic and life practices, she draws out and threads together insights from pain surrounding human vulnerability and the way we can work with and against our own physical (or otherwise) limitations.

Observed in most of these artists’ creative and research practices, autobiography serves as a powerful method of inquiry that bridges the personal, cultural, and social strands of existence, offering a direct lens through which lived experiences are explored and understood. Although the term ‘autobiography’ is not always explicitly foregrounded throughout this thesis, personal lived-body experiences and narratives derived from my own body are woven into the fabric of both the research and the performance practices, indicating an autobiographical engagement. First encountered as personal experiences expressed as testimonial and poetry in the previous Introduction, the thread of autobiography continues its appearance as reflective writing excerpts and poems within Chapter 3 (and in a more embodied sense as an influence on independent art-making) and manifests within aspects of the dialogues, interactions, and creative expressions articulated in Chapter 4. Throughout the thesis, references to ‘the self’ align with autobiographical creative practices, particularly in Chapter 6, when the dynamics between self and other is analysed in relationship to an embodied painscape praxis. In the Conclusion, I discuss more specifically the nuances and challenges associated with such an approach, with an underlying acknowledgment of its value in research projects like this which contain a heavy focus on embodying and sharing lived realities. Such a positioning of the body, as both the subject and object of inquiry, functions as a critical methodology through which autobiography informs and shapes broader inquiry. By grounding abstract theories in the tangible realities of the body, autobiography brings an authenticity that enhances academic discourse, as it relies on embodied knowledge that is both credible and deeply felt (Spry 2011).

In particular and of relevance to this project, autobiographical work in the realm of performance becomes a vital space where personal narrative and artistic expression intersect, allowing artists not only to share, but also to embody and critically engage with their lived realities in ways that challenge

conventional modes of storytelling and/or dominant narratives around identity and the body (Heddon 2008). For instance, performance studies scholar Dee Heddon explores how performers reveal and withhold parts of their experience, mediating between authenticity and audience perception (Heddon 2008: 28-31). She highlights how autobiographical performance can be an act of agency, where the visibility of disability or pain is reclaimed from voyeuristic consumption, inviting a shared yet critically reflective witnessing (Heddon 2008: 48-51). Autobiographical performance becomes a site where the performer enacts lived experience not as a passive subject, but as an active researcher whose body bears essential insights, turning the risk of spectacle into an opportunity for connection.

Additionally, as theatre and dance scholar Lynn C. Miller and her co-editors observe, 'For women, the autobiographical voice is rarely singular, but instead exists in chorus with a cluster of other women's voices' (Miller et al. 2023: 5). Reflective of this, the autobiographical functions as only one facet of this research practice as my embodied experiences and body's narratives are interwoven with those of five other women. This collective approach enables a richer and more nuanced exploration of pain and endometriosis, ensuring that the inquiry transcends the individual and encompasses a broader spectrum of female embodiment.

Whether stemming from social science or artistic practice, the contexts discussed in this section highlight developments in pain expression and art-making. The creative voices referenced provide groundwork for further painscapes art and research, regardless of how pain is explored or its origin. Acknowledging materialising painscape canons and existing research signifies a burgeoning interest in pain communication and representation as an independent field beyond traditional domains. Furthermore, reviewing previous work reveals tendencies and alternative routes for innovative painscape practices. For instance, while many artists in painscapes seem to rely on visual arts or creative writing, my background in performance and multidisciplinary arts offers a unique perspective. Specifically, this research project addresses the underrepresentation of dance practice in painscapes and the scarcity of dance artists creating work from personal pain experiences (Meehan 2023:3). Moreover, this research's focus on the artistic expression of pain experienced by women, particularly related to menstruation or female biology, is both personally driven and academically significant. The artistic outcomes of this project contribute to an evolving art-history canon that increasingly demands substantial representation of women and female artists with diverse experiences of pain, especially those related to female health. By integrating these perspectives, the research underscores the importance of recognising and documenting the myriad ways pain is experienced and expressed, advocating for a more inclusive and comprehensive understanding of pain in art.

Conclusion: Creating with and in Pain

No matter the field or perspective, it is evident that pain itself is challenging to measure, understand, address, and treat (Marchand 2012; Melzack & Wall 1988; Morris 1991; Scarry 1985). Likewise, from the cited strands of pain and pain communication research, it becomes clear that pain, in its invisibility and subjectivity, further shrouds already bewildering diseases like endometriosis, placing

them in deeper uncertainty and doubt. As described eloquently by writer and English scholar Elaine Scarry (1985) in her seminal work *The Body in Pain: The Making and Unmaking of the World*, ‘to have great pain is to have certainty; to hear that another person has pain is to have doubt’ (Scarry 1985: 7). She further indicates that this doubt from others, especially in the medical context, ‘amplifies the suffering of those already in pain’ (Scarry 1985: 7). Often with endometriosis, despite the sufferer’s certainty of her visceral pain, healthcare providers, family, or friends may mistakenly assume the pain is imagined, highlighting a disconnect in communication between those in pain and those who are not.

Reflecting on this disconnect, Sara Ahmed’s writing on the subject becomes particularly relevant. Ahmed explains that pain is impossible to pinpoint as sensation, feeling, or experience because it is ‘bound up with how we inhabit the world, how we live in relationship to the surfaces, bodies and objects that make up our dwelling places’ (Ahmed 2014: 27). Indeed, as she suggests, perhaps the question becomes not so much ‘what is pain, but what does pain do?’ (Ahmed 2014: 27). In this research’s exploration of the communication, expression, and representation of pain, especially in individuals suffering from endometriosis, Ahmed’s question is considered and expanded to inquire: *what can we do with our pain?*

The project explores this by using a painscape practice that, unlike many others which merely draw thematic inspiration from pain, investigates pain as creative material and embodied wisdom. Such an approach generates novel insights into both the articulation of pain and the practices of art. By intentionally working in and with pain through overlapping creative processes, the painscapes sphere is established as a viable and authentic space for exploring endometriosis and other female pain experiences.

CHAPTER 2: SYNTHESISING AN ENDO-CENTRIC PAINSCAPE METHODOLOGY

Introduction: Interdisciplinary Artistic Research

As Chapter 1 underscores, current methods in communicating and understanding pain often fail to fully convey the depth of (endo) pain. Inspired by the limited yet imperative pain-art canon, a nuanced interdisciplinary perspective, not solely reliant on language, might be an effective and robust way to research female pain-related experiences, such as endometriosis, and generate new understandings surrounding them. As such this research employed the creation and contemplation of painscapes to explore the relationship between lived-body experiences of pain and pain expression. In this chapter, I pull out and interweave the theoretical threads involved in this ‘endo-centric’ painscape research, establishing an interdisciplinary methodology drawing from performance/dance, feminist, and disability lenses.

The first section of this chapter explores the connection between improvisation as a creative approach and its application in life practices. This exploration offers insights into responsive strategies to the states of disorientation, uncertainty, unpredictability, chaos, and interruption often encountered in pain or disability experiences. Additionally, this discussion firmly establishes this painscape research in the realm of the performing arts, distinguishing it from the standard social science and visual arts perspectives reviewed in Chapter 1.

The ensuing section contextualises the research as feminist by expanding the concept of ‘interruption’ beyond maternal experiences, as first theorised by Lisa Baraitser (maternal studies and feminist theorist introduced in Chapter 1), to include experiences of endometriosis. By examining both maternal and endo-related interruptions, this section demonstrates how particular female experiences necessitate an embodied improvisational presence, harnessing adaptability, spontaneity, and increased somatic awareness. Inspired by Baraitser’s suggestion that a ‘shift of perspective’ might be needed in the space of interruption (Baraitser 2009: 73), this section illustrates how enduring the pain, discomfort, and disorientation associated with endometriosis might provide unique opportunities for new models of transformation, productivity, and creativity. Indeed, it becomes evident how pain informs its own expression in the creative painscape process.

Following this, and in order to ground endo research in the field of disability studies, I delve into characteristics of crip theory, specifically crip time and crip futurity. Using these concepts, I emphasise how the disruptions related to disability experiences necessitate a similar improvisational mindset and practice. These critical explorations not only illuminate endo’s alternative approach to time, space, energy, and expression, but also enrich the understanding and methodology involved in an endo-centric painscape practice (the processes of which are elaborated upon in Chapters 3-5).

This chapter serves a dual purpose within the narrative of the research journey. First, it firmly situates endo experiences and research within performance, feminist, and disability/crip discourse and practices. This contextualisation addresses the noted scarcity of scholarly accounts of endometriosis,

female pain and gendered chronic pain or gendered disabilities — thereby partially contributing to the overarching aim of enhancing visibility and understanding of the disease in previously unexplored arenas. Second, this chapter reveals the synthesis of theoretical insights which both originated and played a pivotal role in shaping the research methods. As mentioned in the thesis introduction, the reciprocal relationship between theory and practice was extremely fluid and iterative; often making it challenging to pinpoint exact inception points. Therefore, it is imperative to acknowledge that the methodological framework articulated in this chapter emerged over an extended period in an imbrication of theory and practice.

Connecting Improvisational Practices with (Female/Endo) Pain Experiences

The overlaps between an improvisational arts practice and life approach have garnered some attention from dance scholars in the context of disability and acute illness. Accordingly, I first introduce some of this relevant scholarship and highlight the core attributes of improvisation that make it pertinent to endo-centric research. As evidenced below, the focus in much of the literature still remains predominantly on visible disability or intellectual disability rather than the realms of pain, gendered disabilities, or invisible chronic diseases. In response, subsequent sections will illuminate overlooked links between improvisation and the navigation of female experiences of interruption (such as motherhood or endometriosis) as well as the nuanced temporalities of disability/chronic diseases.

Artistic Lens: Improvising in Dance and in Life

In an article written by dance artist and scholar Ann Cooper Albright aptly titled ‘Life Practices’, improvisation is detailed as an embodied life approach transcending artistic process (Albright 2019: 25). Albright outlines how her own movement practice, which involves a foundation of teaching and engaging with contact improvisation, has deeply influenced her life outside of the dancing realm. She indicates that improvisation has helped her ‘survive professional disappointment and physical injury, family trauma, and various lapses in imagination’ (Albright 2019: 25). The specific qualities of *presence* and then *adaptability* as principles of improvisation are expressed as keys to ‘learning to be intentional in the moment’ or cultivating ‘an openness and curiosity’ despite life’s disruptions or chaos (Albright 2019: 26).

In the context of dance and performance, various ways to recount ‘presence’ exist (Doughty 2019: 125). Presence can be described as the development of ‘attention and awareness’ (De Spain 2014: 168); ‘attending’ to something (De Spain 1997:131); ‘being absolutely present’ (Stuart 2010:15); ‘mindfulness’ (Dilley 2015:15); or ‘being awake to situations’ (Mason 2002: 38). States of presence can be described as ‘receptive’ or ‘responsive body’ or ‘perfect attunement’ (Midgellow 2019: 10). The value of presence and ‘being present’ in improvisational practices is extensively argued in dance scholarship as reflected in this referential quote by Chris Johnston encouraging improvisers to:

...be living entirely moment to moment because it's in the spontaneous present that self discovery is possible and creativity lives. In that present, you are more open to receive signals, intuitions, and impulses... (2006:112).

Likewise, in discussing dance improvisation and uncertainty, dance scholar Louise McDowall elaborates deeply upon the many ways dance improvisation involves '... "presencing" a poly attentive body, conversing with ambiguity, uncertainty, potentiality, and choice...' (McDowall 2019). McDowall cites a wide range of various dance practitioners' and philosophers' accounts or definitions of the experiencing of 'this moment' or 'presence' aided by descriptions such as 'feeling lost', 'disorientated', 'dazed', 'elsewhere', 'transported somewhere', 'a zen or zen-like state', or having a sense of 'presence/present-ness' (McDowall 2019: 185-188). Although the exact words vary, 'presence' seems to inevitably connect an improvising body with a different experience of space and time. To me, an improvisational approach within a creative context, or indeed within responding to life's uncertainty, chaos, or disruptions, involves these various descriptions of presence woven together with some combination of adaptability; reverence for the unknown; heightened awareness, and 'somatic consciousness' (Albright 2018: 55).

Albright outlines how her embodied familiarity and kinaesthetic knowledge of this 'improvisational presence' has transformed her being-in-the-world with several examples, but the one I find most related to this project stems from her discussion of life's application of improvisation in the context of caring for a sick family member. This is one of the few discussions I have encountered in terms of drawing a connection between enacting an improvisational practice in creatively motivated contexts and embodying an improvisational mindset or practice in encounters with disability or chronic disease. The way Albright theoretically bridges improvisation with her personal interactions and ethics of caring for an ill body is poignant and resonates with the collaborative research in this project (the collaborative dimension is discussed more in depth in Chapters 4). The bridge she begins to construct in her writing is especially relevant in articulating how trust and intimacy are forged with collaborators by way of improvisation's commitment not only to presence, but also to openness for the unfolding uncertainties of reality.

What is not fully expanded upon in Albright's writing is an improvisational being-in-the-world in the context of a primary experience of pain within her own body or in this case, her brother's relationship with improvisation in his cancer experience. She hints at leveraging an improvisational approach to discomfort which she refers to as 'chaos, disorientation, and the inevitable experiences of falling to the ground...' (Albright 2019: 27). Interestingly, the implicit notion from her writing is that a body in pain or a disrupted body would benefit from a life practice embracing the principles of improvisation, however, she never explicitly states this and indeed, the word 'pain' is avoided. In fact, rather than focusing on incurable pain as such, or chronic interruptions, she favours temporary and acute periods of chaos that ultimately find resolution. The closest the conversation comes to approaching the topic of pain is when she encourages improvisation as a life practice in 'learning to stay responsive in the

midst of life's moments of extreme disorientation' (Albright 2019: 28). Here, she turns to Sara Ahmed's explanation of moments of disorientation as bodily experiences that can be unsettling and cause one's sense of confidence in the ground to shatter (Ahmed 2006: 156). Ahmed indicates that while such feelings 'of shattering or being shattered might persist or become a crisis', disorientation is nonetheless 'vital' (Ahmed 2006: 156).

After reading this and encountering what feels like a tone of nonchalance in Albright's overall discussion of shattered states, I wonder where unresolvable illness or chronic pain sit within this definition of disorientation. Disorientation as described by Ahmed and employed by Albright can be quite clearly linked to the deep internal and external shattering experienced by many who suffer from endometriosis. That being said, I personally would not define my own body's experience of endometriosis as *vital* as Ahmed writes, though I do concur these experiences have thrown my world and my body up from its stable ground. In discussions of disorientation like this, there is a lack of acknowledgement about how pain — and particularly women's pain — situates into this notion of shattering. Likewise, what is the subsequent embodied response to such brokenness or what does it feel like to engage in an ongoing re-discovery of balance over time? How might one reorient during or following such disorientation?

The attributes of dance improvisation mentioned above serve not only as coping and reorienting mechanisms in life practice, but also, as approaches when creatively or collaboratively exploring pain and resilience. My research concurs that those who are indeed shattered by endometriosis and other painful chronic diseases might call on an embodied practice of improvisation. Indeed, the development phases of *Nether Space(s)* and the production itself (all of which are outlined in Chapters 3-5) serve as testaments to the importance of approaching life through the lens of an improviser for those with endometriosis or similarly 'disorienting' diseases.

In another pertinent chapter in the same collection of writings on dance improvisation, dance artist and scholar Sarah Whatley traces the relationship between improvisation, specifically contact and movement improvisation, and disability. The connections put forth by Whatley align with my research in several ways and also, again, illustrate the opportunity for further conceptualising surrounding improvisation in the space of pain and specifically, endometriosis or other unpredictable diseases. Along the same lines as Albright's determination that the concepts from improvisation can be applied to a life approach (including aspects of the care-taking of ill or disabled bodies), Whatley focuses on how improvisational practices, and spaces, specifically within the field of dance, have welcomed diverse and disabled bodies into artistic contexts.

For instance, in her writing, Whatley examines the practice of improvisation not just as a philosophy, but as a tool of inclusion and accommodation for difference — setting up its implicit connection to feminist and crip perspectives/practices. In touching upon the equitable nature associated with improvisation, Whatley states:

Because of the openness and freedom that is associated with improvisation, it is a practice that is often enjoyed by differently-abled dancers. On the positive side, improvisation is inherently emancipatory, embodying values that enable disabled dancers to participate on more equal terms with non-disabled dancers... (Whatley 2019: 408).

Improvisation's sense of democratic inclusivity resonates with feminist and disability discourse, as it undeniably emphasises both individuality and community, amplifying diverse voices. Disabled dancer and choreographer Claire Cunningham (introduced in Chapter 1) encapsulates this sentiment when she describes how her improvisational practice deconstructed and then re-birthed her art-making. She explains, 'crutches became my route to creativity and virtuosic performance' (Whatley 2019: 411), illustrating how improvisation liberated her from conventional 'quest' or 'redemptive' illness narratives of overcoming disability to discover joy, creativity, or in this case, to dance (Frank 1995 as mentioned in Chapter 1; Whatley 2019: 411). Instead, improvisation allowed her to organically develop movement and cultivate her artistic voice by challenging 'the boundaries between ability and disability' (Whatley 2019: 411). Cunningham's experience also highlights how exploring the body's unique physicality within improvisation can bring deliberate attention to lived-body experiences and histories of exclusion. This example used by Whatley showcases how improvisation empowers individuals to embrace imperfection and celebrate body non-normativity, disrupting traditional standards of beauty that privilege a narrow ideal of a dancer as 'the upright, Apollonian, vertical line ascension' (Whatley 2019: 409). She further elaborates, in particular, about the role that contact improvisation has had in 'validating the work of disabled dancers' in the last four decades (Whatley 2019: 409). Whatley puts forth that 'contact improvisation prioritises interaction with different bodies, evolving an aesthetic based on sensory adjustment and accommodation' (Whatley 2019: 409).

It feels instinctive to recognise that improvisation offers freedom and empowerment for both disabled and abled bodies. Within the realm of improvisation, those of us with endo or other similarly wavering pain experiences, are welcomed into an inclusive space where our bodies can move fluidly in response to our cycle, with integrity and respect, which in turn, frequently provides at least an internalised sense of liberation and agency. However, there is some tension around viewing improvisation as such an accommodating and emancipatory practice.

First, there are times when improvisation does not feel accommodating. For me, this is particularly in the context of contact improvisation. Oftentimes, I cannot participate in contact improvisation because of the nature of my chronic disease and accompanying pain. During menstruation or the time beforehand, my body frequently experiences such acute pain that leaving home is not possible and the duet must happen between myself and the space or myself and a camera. In the times when I am able to improvise with another body, it may be a source of embarrassment or self-criticism. In aligning with (visibly) disabled dancer, Catherine Long, the contact improvisational duet form might often be awkward for differently abled bodies when one body feels actual discomfort or pain in certain movement dialogues (Whatley 2019: 418). In essence, Long honestly opens up about how her

physical discomfort and consequently unpredictably fluctuating physical capacities may seemingly limit another person's movement vocabulary or indeed may draw undesired attention to a difference in physicality (Whatley 2019: 418). This sentiment also reflects why using the solo improvisational form or improvising with another person over a virtual space is personally a more empowering practice for my body and perhaps a consideration for those dealing with invisible pain and chronic disease (refer to Chapters 3 and 4 on how this was employed in the research practice).

Next, it seems crucial to acknowledge that for those of us dealing with unpredictable bodies, improvisation may feel more like an obligatory practice instead of an elective. With conditions like endometriosis, where our bodies undergo cycles of change, the lines between able-bodied and disabled become blurred. Chronic or acute pain, especially when it is internally rooted, remains invisible, making the distinction between disabled or able-bodied problematic. Confronting an audience's gaze or consciously drawing attention to lived-body experiences through improvisation may require a different approach for bodies dealing with hidden, socially taboo, and culturally silenced pain. When Whatley discusses disabled bodies, it is unclear whether she is using this phrase to encompass bodies that contend with invisible disability, chronic disease, or pain, or if for her and other dance scholars, disability in dance is only referring to visibly disabled bodies. The phrase 'sensory adjustment' seems like she is implicitly prioritising an improviser's ability to see a disability and respond to a body with an explicit disability, especially when she states that 'disability tends to mark the space before the dance begins' (Whatley 2019: 412). She implies that collaborators or audiences are only able to understand the limitations (and then, unique agency) of visibly disabled bodies. In a contact duet, I would hope my partner, however differently abled we might be, would respond and adapt to the very form and quality of my movement, not just the physical sight of my body which seems to be the focus of this text and others. The very implication that difference is only visible is not accounting for those of us who create and perform through and with unseen pain. As Whatley herself admits, 'the discourse of improvisation rarely acknowledges or records the awkwardness that is about discomfort and pain' (Whatley 2019: 418). This tension is addressed in my research as I direct attention to the notion of invisibility both in terms of disability and in terms of marginalisation.

Finally, tension arises from the assumption that improvisation is the only way disabled bodies can participate in dance or performance. For endo sufferers, engagement in technical or structured movement activities may vary depending on their condition. At times, the rigidness of technique-based forms might be more painful, while at other times, it may be manageable or even fulfilling. This variability also applies to women experiencing menstruation-related pain, irrespective of endometriosis. I attempt to alleviate some of this tension in my approach to painscape research and the production of *Nether Space(s)*, by offering improvisation as a practice alongside or as an alternative to structured movement vocabulary (discussed further in Chapter 5).

Improvisation has the potential to foster agency by empowering individuals to assert control over their bodies and narratives. In this way, engaging with improvisation in an endo-centric practice inherently challenges patriarchal or able-bodied structures that seek to silence female/disability experiences. Moreover, improvisation emphasises embodiment and presence, encouraging individuals to trust their bodily knowledge and to resist mind-body dualisms. Its adaptability and flexibility mirror the resilience needed to navigate the complexities of endometriosis, while its collaborative and inclusive nature fosters solidarity among marginalised individuals and groups. Endometriosis, like many chronic illnesses or disabilities, ‘demands ways of understanding that intelligently address mind and body unpredictability’ (Nielsen 2016, abstract) — in other words the disease necessitates an improvisational life practice as introduced above.

Feminist Lens: Improvising with Interruption

In this section, I establish connections between endometriosis and the maternal experience of interruption. I then build upon improvisation’s methodological role in the research by demonstrating it as an essential tool for navigating female experiences of interruption. By framing endometriosis and endo research within a feminist framework for improvisation, not only are the voices and experiences of those living with the condition amplified, but also dominant discourses surrounding pain, disability, and femininity are challenged — ultimately contributing to a more inclusive and empowered understanding of female lived experiences as well as improvisation as a life practice.

Interruption is defined as a break in continuity. Although often discussed in global terms such as maternal career or life disruption (Orenstein 2000: 33), Lisa Baraitser’s work on maternal subjectivity delves into the relentless interruption that permeates the lived experiences of mothers on a moment-to-moment basis. Baraitser examines how maternal care impacts maternal time, discussing how it:

...is elicited by a ‘command’ made by the other which constantly interrupts, bringing her to a myriad of points of disjuncture... She finds herself embedded in certain durational experiences from which she is disturbed... (Baraitser 2009: 75).

In the chapter titled ‘Maternal Interruptions’ in her book *Maternal Encounters: The Ethics of Interruption*, Baraitser reflects on her transition into motherhood, sharing:

The cry pulls me out of whatever I was embedded in, and before I have a chance to re-equilibrate, it pulls me out again. There are days that follow nights that follow days in which I am punch-drunk from interruption (Baraitser 2009: 66).

Baraitser’s reflections on the interruption of maternal time resonate with the experiences of individuals with endometriosis, where the cries of pain from one’s own body echo the demands of a newborn. The overtones of motherhood, including embarrassment, discomfort, shame, exhaustion, numbness, frustration, and shock (Baraitser 2009: 4), parallel the overwhelming undercurrents

experienced in endometriosis. This irony is particularly poignant given that endometriosis, a disease that can lead to infertility, shares characteristics with the experiences of motherhood.

Similar to the feeling of being thrust into and pulled out of a durational experience, which Baraitser writes of motherhood, the individual suffering from endometriosis is expected to and indeed, must, in order to overcome the disruption, 'right herself' over and over again (Baraitser 2009: 68). In the case of endo, the unrelenting interruptions which manifest as physical, emotional, and psychological pain, sever the flow of time, space, and body — contributing to an overall staggering sense of uncertainty. Likewise, consequences of the disease such as surgical procedures, recovery intervals, doctor visits, or reproductive technologies like IVF, to name a few, punctuate and distort the normal routine and flow of time with disorientation, breaks, gaps, and precariousness. All the while, the individual is expected to have sustained presence and perseverance despite the 'nightmarish intensity' of such repetitious disruption (Baraitser 2009: 67). The constant and vicious cycle of re-balancing and re-negotiating time, space, mind, and body is daunting. The energy devoted to containing this daunting-ness behind a veil of secrecy for the sake of maintaining sociocultural norms is all consuming. The pain, as if an infant or child, demands the woman to 'respond to me' and 'deal with me' not later, but now, in the immediate instant (Baraitser 2009: 68).

Baraitser writes, 'interruption constantly re-establishes the present by demanding a response now' (Baraitser 2009: 66). In the experience of mothering as she discusses, or in suffering from recurring pain as relevant to this research, the body is pulled out of the natural rhythm and passage of time and, similar to engaging in an improvisational practice, moves instead within the here and now. This repeated reconnection and pivot to the present moment is analogous to the way one might engage with time in an improvisational arts practice. In both cases, the body's relationship to time carries a sense of immediacy and instability. For the sake of innovation and authenticity, the improvising body must create by abandoning expectation and judgement. In seeking relief, the endo body must meet particularly challenging moments with spontaneity and intuitive somatic awareness. Being in the world in such a way requires an attunement and awareness reminiscent of the distinctive embodiment and orientation to space and time described by many improvisation based artists or performing arts practitioners as 'presence' (Biasutti & Habe 2021) which provides a focus for investigation throughout this research practice.

Emphasising an improvisational presence which incorporates adaptability, somatic consciousness, and heightened awareness (among other improvisational traits and definitions of presence described in the first section) can set the tone for 'expanding one's sensibilities' (Doughty 2019: 125). Additionally, improvisation can induce participants to 'create an alternative world in which complex processes and feelings are activated' (Kloppenber 2010; Minton 1997; Morgenroth 1987). Likewise, in the world of dance improvisation, movers can become so attentive and concentrated beyond distractions that their complete absorption in the movement or performance may 'enhance a loss of self-consciousness and even a sense of time' (Biasutti 2016; Hefferon & Ollis 2006).

Some of these aspects are prerequisites and manifestations of presence or presence functioning at its highest level, flow.⁸ Flow, which in dance is essentially a heightened sense of presence, is most basically defined as a state in which people are so involved in an activity that nothing else seems to matter (Csikszentmihalyi 1990). Experiencing time in such a uniquely somatic and feeling-based mode can lend itself to entering what feels like an alternate realm of consciousness which in fact is simply the allowance of non-traditional modes of sensing, feeling, being, and creating. For instance, in my arts practice I use improvisation either to produce new movement vocabulary or to ignite new pathways of artistic expression with the aims of either embodying a deep level of presence most of the time or entering a state of flow when possible. In any case, I enter a different space and time with an intended abandonment of the past in order to allow for a creative present and new future.

However, accessing such a state of presence is significantly different in moments of excruciating pain, despite the existence of the same somatic awareness and erasure of past and future. Over time and after years of corporeal disruptions, I have adapted out of necessity, and learned to flow with the pain and listen to my body in a manner akin to improvising, enabling ‘new ways of considering and acting’ (Midgellow 2019: 10). Cultivating presence while in pain, at the very least, has allowed me to connect to my breath in order to prevent the rise of overwhelming panic.

In the collision of interruption and receptivity, whether in presence or deep in flow, an individual is pushed into an ‘eruption of being’ (Appelbaum 1996: 30). Similar to improvisational action in the context of movement and performance, when an individual is willing to be receptive and vulnerable, awareness transcends the cerebral and draws instead from kinaesthetic instinct. In embracing a more somatic way of conceiving of time and space, the individual is welcomed into a rhythm of unfolding which is less concerned with habitual thinking or repeated patterns and more attuned to sensation, expression, and therefore, creation. The embodiment of improvisation as ‘a kind of deliberate staying in the present’ allows for moments of surprise, of self-knowing without rigid meanings, and of challenging preconceived notions of productivity or contentment (Baraitser 2009:83).

An intriguing way of considering the generative potential of interruption through the lens of improvisation comes from dance improviser Nancy Stark Smith. She hones in on moments that unfold ‘between reference points of previousness and futurity’ (referenced in Midgellow 2019: 10). Referring to these moments as being ‘in the gap’ she writes:

⁸ Furthermore, as Doughty points out, in much improvisational discourse, Mihaly Csikszentmihalyi’s concept of ‘flow’ also offers direct and useful parallels particularly in relation to the concept of presence in its emphasis of self-awareness in the immediate, actionable moment (Doughty 2019:122). Often, improvisers across art-forms strive to achieve the penultimate connection to the present moment as realised in ‘flow’ states. Achieving a state of flow and embodying hyper-awareness in the present moment are related to one another, but not necessarily the same experience. Both presence and flow are considered a means of creativity, authenticity, and originality in both improvisation and in a host of other activities, although flow is arguably more complex and nuanced, requiring a level of challenge, effort, and freedom that might not be required in presence (Csikszentmihalyi 1993: 67).

Where you are when you don't know where you are is one of the most precious spots offered by improvisation. It is a place from which more directions are possible than anywhere else. I call this place the Gap. The more I improvise the more I am convinced that it is through the medium of these gaps – this momentary suspension of reference point – that comes the unexpected and much sought after 'original' material...Being in the gap is like being in a fall before you touch bottom. You're suspended – in time and space – and you don't really know how long it will take to get 'back'... (Stark Smith 1987: 3).

The gaps she references hold creative potential by providing opportunities to feel the world with a reverence and curiosity for uncertainty. Without the noise of what exists outside of the gap, an individual is open to a new world brimming with unknown possibilities and the spectrum of humanity. In an arts practice such gaps are sought after in order to access deep levels of creative ingenuity and authenticity. Indeed for some individuals discovering 'flow' or being 'in the moment', is exquisitely liberating and a channel for pleasure or joy. In contrast, however, for others it may be excruciatingly unfathomable given their material circumstances.

For example, while these gaps exist for the sleep-deprived new mother or menstrual migraine sufferer, they autonomously and uncontrollably arise. In the case of the latter, all we can do is meet these gaps with the courage to be present, intuitive, and responsive, despite the fear, chaos, and unknowns that materially exist within a localised, pained moment. Seemingly disruptive interruptions, whether from pain or other life circumstances, can summon new forms of self-experiencing that privilege the sensory and the somatic. Repetitive interruptions in time and space may suspend the opportunity for reflective thinking. However, as in the practice of improvisation, it may lead to an organic responsiveness and intuitive openness to the unfolding moment and ultimately, an ability to sustain presence and persevere in the realm of the immediate 'here and now'. After years of moving in and out of the gaps, I have acquired the ability to anticipate the unforeseen and instinctively prepare myself for spontaneity — a skill closely linked to the anticipatory readiness in some forms of crip time, as explored in the following discussion. It is this very mode of embodied receptivity and flexibility, a through-line for this research, in which moments of unique connectedness and/or transformation may unfold.

Of course, distinct differences separate the 'seemingly endless series of "microblows",' of motherhood discussed by Baraitser (2009: 69) and the 'microblows' of endometriosis. Namely, unlike motherhood, which involves nurturing a child and fostering unconditional love, the interruptions from endo and other chronic illnesses or chronic pain conditions lack this specific transformative potential. However, witnessing the interruptive nature of both, we move towards seeing overlapping subjectivities defined by: heightened sentience; an enlivened awareness of one's emotional range and vulnerabilities; and a non-linear temporal consciousness that places less weight on past and future (Baraitser 2009: 4). As our bodies improvise with and against the rhythm of interruption, our attention

can become more grounded in cultivating a new, changed relation with ourselves and less grounded in trying to defeat the disturbance of our temporality, spatiality, energy, identity, or corporeality.

Instead of ‘trying to get back’ to what she was saying, thinking, or doing, the woman suffering from cramps or a migraine (as the mother caring for a new infant) accepts the interrupted time as an experience ‘beside herself’ — a moment of coming undone and coming back together anew (Baraitser 2009: 75). Such an improvisational life approach, which itself takes time, commitment, and practice to uphold, is what Baraitser seems to be calling for in order to realise the generative potential of interruption. Undoubtedly, holding such a space, for interruption to transcend disruption requires tenacity, resilience, and endurance, particularly when experiencing pain. But it is in this space, a ‘nether space’, wherein we might discover agency and creativity in the midst of pain (elaborated upon in the description of *netherness* in Chapter 6).

Disability/Feminist Disability Lens: Crip Identity & Crip Time

The above analysis sheds light on lived experiences of interruption as well as the practices used to navigate such. This improvisational ‘mode’ includes embodying presence, heightened awareness, adaptability, and somatic consciousness — attributes highlighted in relation to application of dance improvisation in life practices. Building upon the foundation established by Baraitser’s exploration of interruption in the context of motherhood, the discussion now turns to the intersection of feminist and crip perspectives in understanding female disability experiences of interruption, particularly in the context of endometriosis. Crip theory offers another framework through which to understand these life experiences and practices yet with a honed focus on the interruptions caused by disability and pain. Similar to the previous section, disability or pain disruption can be caused by external factors such as environmental stimuli, societal norms, or systemic barriers, as well as internal factors such as bodily sensations, emotions, or cognitive processes.

In this section, crip time, in particular, is framed as a specific manifestation of improvisation related to navigating the ‘strange temporalities’ birthed by disability and pain’s disruptions (Kafer 2013:38). Before exploring crip time, it is important to more clearly define crip theory and its relationship to understanding disability. Crip theory, rooted in disability studies, offers a critical lens through which to examine disability as a social construct rather than solely a medical condition (McRuer 2006). It challenges normative conceptions of ability and normalcy, advocating for the recognition and celebration of diverse embodiments and experiences. At its core, crip theory seeks to dismantle ableism — the systemic discrimination against people with disabilities — and promote disability pride and activism (Kafer 2013).

Central to crip theory is the concept of crip identity, which encompasses the lived experiences, perspectives, and identities of individuals with disabilities (McRuer 2006). Identity exploration is a natural part of reflecting on and sharing personal body experiences and is a crucial aspect of any painscape research methodology (Padfield in Gonzalez-Polledo & Tarr 2018: 221). In the context of

endo-centric research, exploring agency and identity through a crip lens can be particularly illuminating. Crip identity embraces disability or chronic disease as a fundamental aspect of one's identity, rejecting notions of disability as inherently negative or inferior. Instead, it celebrates the resilience, creativity, non-conformity and unique perspectives that arise from experiencing the world with a disrupted orientation to various aspects of existence, including space, time, and one's own body. In the case of endo, crip theory and crip identity can be specifically deployed to better understand and amplify how individuals navigate the temporal complexities of an invisible, gendered disability.

In her seminal book *Feminist Queer Crip* (2013), feminist scholar Alison Kafer, as mentioned in Chapter 1, particularly highlights the absence of discussions on time, temporality, and futurity within disability studies, noting that these themes are more commonly animated in queer theory (Kafer 2013: 27). She critiques the prevailing tendency to frame disability within a 'curative' temporal framework, which again echoes the 'quest' narrative structure often found in illness narratives emphasising triumph over acute disease (as mentioned in Chapter 1 in Frank 1995). In response, she proposes an 'elsewhere' (Kafer 2013: 24) where disabled bodies can exist outside these oppressive frameworks, envisioning new ways of being and relating. This concept of 'elsewhere' challenges normative understandings of disability and temporality by imagining alternative futures and spaces where disabled bodies are not marginalised. Her perspective aligns with Tobin Siebers' observation in *Disability Theory* (2008) that pain is often portrayed in redemptive frameworks, contributing to an ableist narrative of improvement and newfound abilities (63). In an effort to engage with and represent these other identities and contest the linear, progressive view of time that sees disability as something to be overcome or eradicated, Kafer brings forth the concepts of crip time (and by extension, crip futurity) which I view as an embodied manifestation of improvisation.

In some disability experiences which might involve interruption, an individual's crip engagement with time is similar to the improvisational mode enacted in maternal experiences of interruption. While crip time and improvisation intersect in these contexts, they are not totally synonymous. In this research, they represent different discourses that contribute to a more inclusive understanding of endo experiences and realities. Crip time's multidimensional shaping and shifting of time resembles improvisation, as both appear to acknowledge the variability and unpredictability of bodily experiences and responding through heightened awareness, adaptability, and a shift towards an embodied, more feeling-based way of 'going about things' (Mizell 2019: 7). Both strategies highlight the importance of acknowledging and accommodating diverse experiences and perspectives, whether related to disability, pain, gender, or other forms of marginalisation.

However, crip time specifically focuses on temporal experiences and perceptions within the framework of disability. It refers to a reimagining or redefinition of time from the perspective of disabled individuals, particularly those who experience disruptions associated with chronic pain or disability. It challenges normative understandings of time instead embracing the fluctuating,

nonlinear, and individualised experiences of time that arise from living with, in the case of endo pain. In many cases, crippling time extends time, opening us to a slower way of being in the world in accommodating the experience of a range of (im)mobilities. Sometimes additional time is needed to arrive somewhere or accomplish something: equipment such as hearing aids or wheelchairs can malfunction; slower gaits or dependence on caregiver can cause delays; and various ableist boundaries might cause disruption. However, crip time transcends the addition or subtraction of time. Beyond the sheer extension of time made available to those with a differently abled body, as employed within this research, crip time refers to ‘flex time not just expanded but exploded’ (Kafer 2013: 27). Stretching and resisting normative modalities that define time, such as productivity, accomplishment, and efficiency, crippling time and championing other ‘eccentric economic practices’ can urge us towards something different (Kafer 2013: 40). For instance, shaping work-life schedules or more specifically, art-making practices, according to one’s body’s fluctuating needs, desires, and abilities demonstrates a refusal to strive for sociocultural standards of ideal, average, or normal. Such an attuned somatic awareness supports the reorientation of time itself. As Margaret Price explains:

Adhering to crip time...might mean recognizing that people will arrive at intervals, and designing [events] accordingly; and it might also mean recognizing that [people] are processing language at various rates and adjusting the pace of conversation. It is this notion of *flexibility* (not just ‘extra’ time) that is of significance. (Price in Kafer 2013: 27)

Endometriosis pain is like and unlike other forms of disability or chronic pain in how it perpetuates without a curative treatment for an unpredictably, and frequently, indefinite period of time. The chronicity establishes a certain ‘shapelessness in time’ especially in conventional work-life temporalities (Freeman 2016: 336). Endo narratives can be viewed in a similar manner to chronic disease or disability as ‘out of place temporally...no one knows whether the painful state will improve, deteriorate, or remain the same’ (Jackson 2005: 344). The chronic and cyclical nature feels ‘unrelatable to modernised timescapes’ (Przybylo & Fahs 2018: 222) and signals, similar to Kafer’s framing of crip time, a queer relation to time for those with menstrual or endometriosis pain as ‘ebbing and flowing in varying degrees of intensity and insistence, compression, and dilation...’ (Freeman 2016: 339).

Up until this point, crippling menstrual pain, intense blood loss during menstruation, and debilitating menstrual migraine are rarely located in discussions of temporality. In a co-authored article entitled ‘Feels and Flows: On the Realness of Menstrual Pain and Crippling Menstrual Chronicity’, Ela Przybylo and Breanne Fahs argue that a deeper reading of menstrual pain is needed particularly in relationship to ableist and non-menstrual models of productivity and time (Przybylo & Fahs 2018: 216). Instead of implying more drug therapy or science is required to manage this kind of corporeal experience as often implied in the conclusions of social science and science-based pain studies, (Grandi et al. 2012; Mathew, Dun, & Luo 2013; Walsh, LeBlanc, & McGrath 2003) perhaps enhanced understanding and validation of endometriosis or menstrual pain might occur by reframing

perspectives and accessibilities originating from this distinct, temporal kind of disruption. Ultimately then, might endometriosis and/or menstrual pain warrant alternative modalities for work and life, thereby encouraging other kinds of temporalities and ‘futures that support multiple ways of being’? (Kafer 2013:45). If crip time ‘bends the clock to meet disabled bodies and minds’ as Kafer suggests (Kafer 2013: 27), does it also bend the clock for bodies suffering from endometriosis or related cyclical pain?

As discussed briefly by Kafer, crip time can manifest as ‘anticipatory scheduling’ which may lead to what feels like measuring the present moment against the moment to come (Kafer 2013: 38-40). In this specific enactment of crip time, Kafer refers to an individual experiencing an ‘embodied dualness’ in relation to this conceiving of the body in the present and the future. For example, those who live with chronic fatigue or pain, might negotiate time by asking themselves, ‘if I go to this talk now, I will be too tired for that class later; if I want to make that show tomorrow, I need to stay home today’ (Kafer 2013: 39). Those with unpredictably disruptive diseases, like endo, operate according to how we might conserve or distribute energy in anticipation of when pain might reach a pinnacle in our menstrual cycle. This reshaping and personalised observance of time in expectation of future interruptions benefits from considering improvisation’s relationship to the immediate present, the unknown future, and unpredictable interruption. Incorporating crip time and by extension, a crip futurity perspective become vital concepts and practices in both reimagining a future for our fluctuant bodies and for drawing attention back to the present ‘here and now’ of such bodyminds. Through improvisation and a crip lens, we can begin to read this practice of self-care not as preserving one’s body for productive work, but as refusing ‘normal’ temporality and routines in order to make room for joy and creativity. Adopting an improvisational attunement to the body, even as it stretches between a disrupted present and an uncertain future, invites spontaneous and creative routes for resilience and embodied agency.

Over time, my creative practice has been shaped by this embodied dualness, which for me originates from endo pain; this is a realisation I only fully grasped through this research. In hindsight, throughout my professional journey in the disciplines of dance, performance art, immersive performance, and live painting, the content of my art may be indirectly influenced by endometriosis, but certainly the practice and indeed, the journey itself have been directly impacted by the disruption in space, time, and body caused by the disease. Through unforeseen and anticipated disruptions, I have gathered embodied expertise in navigating interrupted and uninterrupted time — oscillating between a woman in pain and a woman remembering pain. At this point, I now recognise that this embodied dualness or indeed, liminal state between present and future or sometimes between present and past, originates not only from my past, present, and future endometriosis experiences, but also, through new interruptive experiences with mothering a young child. In both experiences of interruption, interludes of creative opportunity are usually quite brief and as unpredictable as ‘the gaps’ themselves. The combination of brevity and unpredictability births a sense of urgency and requires harnessing a state of presence or flow almost instantaneously. I create with a sense of attack,

acknowledging that at any given moment, I might not have the opportunity to explore impetuses without disruption or disorientation. If flow seems unattainable within these pursuits, I aim to, at the very least, carve out concentrated moments of presence and attempt to honour the unknown with curiosity and experimentation in these bursts. Trusting the concepts of spontaneity and presence, which are central to an improvisational approach, seemed to afford a crip time mode of creating that invited ‘the emerging, the imperfect, and the unfinished in both aesthetic and ideology...’ (Midgelow 2019: 3).

Undeniably, the consideration of crip time is connected to improvising with endo interruptions, and in my capacity as researcher, once this comprehension was pinpointed, I aimed to internalise this emphasised insight in the unfolding creative practice. Confronting the temporalities of pain — ‘which bind a community through shared experiences and collective endurance’ (Baraitser 2012: 118) — I hoped my research and art could more meaningfully drive real sociocultural change across a variety of contexts. The use of painscape practices in relation to exploring and challenging themes of time and embodied agency will be further elaborated upon in Chapter 3. Additionally, by embracing crip time, the research extends into the domain of crip culture and forges a specific crip space for endo bodies in the realm of netherness.

Conclusion: Weaving Improvisation, Feminist, and Crip Principles into Painscape Research

From the project’s outset, this endo-centric research was inherently driven by artistic, feminist, and disability values. This chapter pinpoints these values and other common philosophical traits across the respective fields in relation to endometriosis, and more broadly, female pain research. To begin with, prioritising the historically trivialised, lived-body experiences of women naturally aligns the painscape research with the overarching emancipatory goals of feminist and disability activism: to empower communities who are systematically oppressed, under-researched, under-represented, disadvantaged, and/or voiceless including menstruators, women in pain, endometriosis sufferers, and women artists (Danieli & Woodhams 2005; Groat & Wang 2001; Sandahl 2003). Moreover, as outlined in this chapter, the emphasis on emotion, intuition, personal experience, reflexivity, creativity, diversity of perspectives, alternative modes of understanding, and curiosity propelled the research deeper into an interdisciplinary (artistic, feminist, disability) methodology dedicated to authenticity and expression (Hesse-Biber & Leavy 2007; Lafrance & Wigginton 2019; Pedersen & Haynes 2015).

Furthermore, foregrounding women’s lived-body experiences of pain and disability with intention and in such an interdisciplinary nature exposes obvious connective points between intersectional subjectivities. Consequently, this chapter highlights important intersections between the various discourses, namely, the concepts of disorientation, interruption, and crip time/identity, with improvisation as a through-line. Weaving feminist and disability perspectives together, using improvisation as life and artistic strategy, not only establishes the methodological framing for the subsequent chapters, but also offers new ways to understand and respond to the endo-related

experiences of disorientation, interruption, chaos, invisibility, or discomfort. As a result, these aligned perspectives allowed for a new model of endometriosis pain and menstrual pain as not just depleting and disruptive, but generative and complex.

This chapter connects and redefines ways of living with, thinking about, and expressing endometriosis — establishing a bespoke methodological perspective grounded in lived experiences and practices. This trifecta lens of improvisation, feminism, and crip theory is useful for the discursive fields and also for this research as it supports: the reconstruction of ableist temporalities; the problematisation of ableist narratives of betterment; and the allowance for reflection without being consumed by negativity. Indeed, as was the case in this research, opportunities to reconsider one's relationship to time, productivity, ability, and the body become more accessible. Embodying these shifts, we can realise new directions in art-making and by extension, the way we live with the uncertainty, disorientation, and interruptions of pain.

CHAPTER 3: PHASE I: PAINSCAPE RESEARCH PRACTICE — INDEPENDENT ART-MAKING

Introduction: The Gestation Period

As mentioned in the Introduction, this artistic research can be loosely divided into three phases. The first two phases contributed to the development and shaping of the methodological threads introduced in Chapter 2, while also being influenced by them. Phase I, the focus of this chapter, commenced during the second trimester of my pregnancy, revealing an intriguing parallel between the gestation of my son and the ripening of the research. The independent experimentation during this research stage laid the foundation for the entire project. Phase II, detailed in Chapter 4, included interactive exchanges with five endometriosis sufferers: Jessie, Toby, Chelsea, Mei, and Danielle (permission received in consent forms to use their first names). As Chapter 4 will demonstrate, these two channels of creative practice iteratively empowered each other.

In the first part of this chapter, I describe the emerging practices within Phase I's six-month incubation period (January 2021-June 2021). During this time, I engaged in solo art-making, creating 'painscapes' via improvised practices and regular video documentation. Using dance, paint, film, ritual, and words, I intuitively allowed various body-focused processes and forms to naturally develop from and fold into and out of one another, concurrently extending into and out of theory. Unlike my typical improvisational art-making, which often stems from more subconscious inspirations, I initiated this research by deeply engaging with autobiography (as revealed in Chapter 1): my embodied pain history and current experiences of interruption, disorientation, and invisibility related to endometriosis, using them as points of departure.

By centring the practice on the navigation and expression of these endo experiences, my reliance and exploration of the methodological attributes and strategies discussed in Chapter 2 intensified. As previously noted, these attributes and strategies include adaptability, reverence for the unknown, presence, heightened awareness, somatic consciousness, crip time, and co-creativity. Accordingly, artistic practice, lived experience, and theory began to converge. In the latter half of this chapter, I unpack this convergence and discuss how it supported the advent of particular artistic and conceptual themes. The evolution of these thematic threads — including embodied agency, time, and the expression/representation of endo's invisibility both in the sense of marginalisation and its inability to be seen — felt integral to the research path.

In addition to detailing the methods in conventional academic forms of writing, this chapter⁹ (as well as Chapters 4 and 5) includes interjections of written reflections, imagery, poetry, and video links to

⁹ For clarity purposes, please note that these interjected documentations, along with the portfolio links provided in the 'Emerging Practices' segment of this chapter and the 'Traces of Pain' segment of Chapter 4, are not the final artistic submissions of this project. However, they are essential in showcasing the creative evolution of ideas and practices that led to the final artistic outcomes (*Nether Space(s)* and the kinaesthetic painting performances detailed in Chapter 5) and the inception of the concept of netherness (another research outcome described in Chapter 6).

effectively represent the artistic research. For instance, the italicised excerpts highlight the specific pain memories or reflections that informed or emerged from the creative modalities during this phase. Imagery and videos provide insightful glimpses into the practices and creations, complementing textual descriptions. This fusion of written and visual elements seeks to elucidate how my personal pain was transmuted into artistic expression, acknowledging the complexity and challenges inherent in articulating this process.

The Emerging Practices

Movement Meditations: Improvisation & Choreography

Digital Archive: <https://www.feelherpain.com/improvs.html>

On a weekly or bi-weekly basis, I delved into movement research in the form of improvisation or choreography. Occurring at the height of the pandemic, domestic spaces like the living room, the bathroom, the anticipated nursery, and the porch, were transformed into creative work sites. In one to three hour stints, I entered these repurposed spaces with the intention of expressing and reclaiming my journey in and out of pain through dance. I experienced these sessions as ‘movement meditations’. For instance, before initiating movement, I began in stillness, actively recalling and/or meditating on the multidimensional suffering induced by my struggles with endometriosis. These initial pauses seemed to invite a profound synchronisation between mind and body. Then, I physically and emotionally embodied and explored personal experiences like enduring severe menstrual cramps, migraines, back pain, surgery, recovery, or IVF-related activities. These improvisations were executed in silence and/or frequently with an instrumental or electronic musical score. Despite a distinct attunement to endo and pain, the movement was likely influenced by both conscious and subconscious impulses. Eventually, I would integrate not only my experiences, but those of the collaborators.



Figure 1. Phase I Practice: Screenshot from Movement Meditation Documentation (January 2021)

'I didn't die from pain, but as I reflect back on my most painful episodes, I feel like a part of my

spirit would indeed perish and my responsibility would then become a rebuilding of my broken self until I felt reborn. My pain experiences can be summarised as a series of deaths and rebirths... (Personal Reflective Writing, January 2021)

Significantly, the initiation of these movement meditations occurred during pregnancy. While they were not always rooted in current endo-related pain due to the absence of menstruation, they drew on embodied memories of pain. Notably, when my endo symptoms returned in Phases II and III, and I worked more directly in and through substantial pain, the movement expression felt analogous to these preliminary improvisations. Using heightened somatic awareness and improvisational instincts, I could deeply engage with my pain whether past, present, or future.



Figure 2. Phase I Practice: Screenshot from Movement Meditation Documentation (January 2021)

In this phase in particular, I experimented with an ‘unsteady’ space (Duggan 2012: 72) between the tangible reality of pain and the representation of pain memories embedded in my body. These explorations gave rise to movements that captured the essence of a body in pain rather than directly expressing current pain. The improvisations, where I constantly moved between reality and memory, mirrored the concept of mimesis¹⁰ (Taussig 1993:47-8) or ‘mimetic shimmering’ (Duggan 2012: 74). This dynamic kept both imagery and body in a state of ‘undecidability’ (Duggan 2012:74), blending visceral discomfort with curiosity and reflection. Was I genuinely experiencing pain, or portraying it? It was sometimes an unsettling tension.

¹⁰Though similar to embodiment, mimesis in dance and performance refers more to the imitation or representation of real-world elements through bodily movement and expression. This concept finds its roots in ancient Greek philosophy, notably discussed in Aristotle's ‘Poetics’. Postmodern scholars have further explored mimesis, considering its complexities in contemporary performance contexts.

'It's almost as if "my cramps" or "they" are like unwelcome terrorists invading my body and torturing me. "They" are characters in the unfolding of my life's story who can't, who won't leave me the fuck alone. They want to violate me and sabotage my dignity. Somehow over the years instead of just cramps, they became "my cramps" as if I owned them when in fact, they owned me.' (Personal Reflective Writing, February 2021)

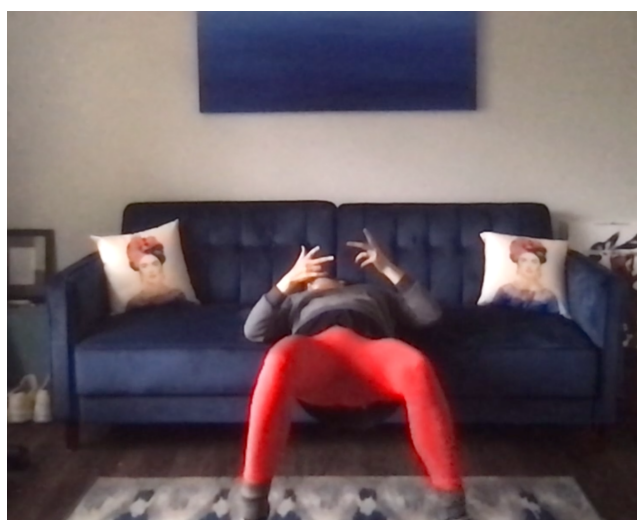


Figure 3. Phase I Practice: Screenshot from Movement Meditation Documentation (February 2021)

As a result of these movement practices, I generally began to question the term ‘memory’¹¹ as a sufficient descriptor for what my body and mind seemed to access in terms of endo embodiment. Indeed, as this project unfolded, it became increasingly apparent that endometriosis experiences and pain persist as an indelible residue never fully eradicated from the body. Amplified by interactions with the other women, the movement research (as well as other practices described below) continued to indicate that pain remained easily accessible and recollected through creative expression, irrespective of the current state of physical suffering. I discuss the experience of time in relation to endo, this improvisational process, and crip theory more in depth in the second half of this chapter. Suffice to say, these movement meditations, a core element of my practice, expanded into specific

¹¹The realm of memory studies is extensive and beyond the scope of this dissertation. However, this research aligns with and draws inspiration from philosopher Thomas Fuchs' concept of embodied memory which emphasises that memory is not merely a cognitive process but is deeply rooted in the body. He identifies several types of body memory, such as procedural, situational, inter-corporeal, pain, and traumatic memories. These memories are formed through our physical interactions and experiences, becoming part of our bodily knowledge and influencing how we perceive and react to the world around us. This perspective integrates phenomenology and cognitive science to understand how memories are stored and recalled through bodily experiences (Fuchs 2016).

performance or choreographic ideas in conjunction with associated writings, visual art, or filmed performance art as described below.



Figure 4. Phase I Practice: Screenshot from Movement Meditation Documentation (February 2021)



Figure 5. Phase I Practice: Screenshot from Movement Meditation Documentation (March 2021)

'Pain comes even when I am not actually menstruating. In high school, I remember running a one mile loop for field hockey practice one day and at the end of it I got severe cramps which were akin to my menstrual cramps. I doubled over, and instead of running back like everyone else, I hobbled back like a hunchback as the panic of pain started to rise within me. If I recall properly, I had to talk to myself aloud to keep myself calm... Running or cycling became obvious as triggers for endo pain throughout my life, but at that point, no one could relate the two

things. Again, I was brushed off by my coaches as having a weak body that just couldn't handle endurance training. How wrong they were.'
(Personal Reflective Writing, February 2021)



Figure 6. Phase I Practice: Screenshot from Movement Meditation Documentation (March 2021)

Body Painting

Digital Archive: <https://www.feelherpain.com/painscapes.html>

On a similar weekly to bi-weekly basis, and often in the same converted spaces, I engaged in a dynamic painting practice. I categorise this practice as a body-forward ritual due to its kinaesthetic dimension and the absence of any painting tools other than the body itself. Much like the inauguration of the movement meditations, I mindfully considered my body's pain story before engaging with the paint. In those preemptive moments of accessing pain, I reminded myself that my specific visual art skills would convey an atmosphere or essence of pain rather than a literal representation. After this brief yet focused contemplation, I commenced the painting process without any preconceived outcomes, channelling pain and/or its residue into the work.

'I'm not sure if I had time or energy to tell my friend that I needed to go outside, or if I just ran outside (hobbled outside) – I got to the small alleyway behind the building and passed out. I couldn't have passed out for too long, because she was there when I opened my eyes and helped me up and gave me some water. She then called

a cab for me and proceeded to explain in Chinese to the driver to take me to the closest hospital. I was in agony on the car ride, unable to speak or acknowledge the driver in any way. I was feeling dehydrated and feeling numbness in my hands from the anxiety of just having fainted in an alleyway. At this point, as my uterus contracted and the terrorists came in for another assault, I became nervous I would shit myself in the cab. Between the physical pain and the draining anxiety and fear of the pain, my mind and body spun out of my control.' (Personal Reflective Writing, March 2021)



Figure 7. Phase I Visual Art Practice: Photograph of Painting (January 2021)

Rather than concentrate on visual outcome, the emphasis was on the embodied actions of painting: the mixing of the paint; the application of the paint with body rather than brushes; the gestures associated with painting or with concealing/revealing the final painting; the location/site specificity of the painting; and the filming of the painting actions. This style of painting engendered a sense of pause and recollection throughout: physically and emotionally difficult experiences associated with endometriosis seemed to surface as the paint touched my skin and the surface of wood or canvas. In Phase I, in response to the embodied memories rising to my conscious imagination, the physically violent nature of endometriosis symptomatology emerged as prioritised impetus: the stabbing, aching, disabling, ugly, exhausting, out of control, hidden pain. For example, gentle stroking of the canvas with my hands was replaced by gripping it with tense fingertips, mimicking the pulling sensation

characteristic of my pain episodes. Immediately following the act of painting, I would reflect on the experience through text. These written reflections, in communion with the paintings themselves, were often illuminating in terms of both the experience of endometriosis and the process of creating painscape art.



Figure 8. Phase I Visual Art Practice: Photograph of Painting (February 2021)

'In the refuge of the bathroom, a place that has become my safe space over time, my usual experience commences. My physiological response to the pain like this has been pretty consistent. First, it starts with me feeling increasingly hot and anxious. Then, I feel the need to push - it's like a false labour is happening, but instead of a beautiful baby, I push out my insides and my guts and literally, shit. I shit as a biological reaction to the cramping pain -- it's totally and utterly uncontrollable. I also get so overheated at this point that I begin to sweat from the pain and the fear of the pain and whatever else is happening in and to my body. I unconsciously strip off all my clothing and I begin to shake and have chills while still feeling heated. I feel my insides twisting and torquing in reds, browns, deep blues

and what feels like the blackness of night.'
(Personal Reflective Writing, March 2021)



Figure 9. Phase I Visual Art Practice: Photograph of Painting (March 2021)



Figure 10. Phase I Visual Art Practice: Photograph of Painting (April 2021)

Through this tactile and mindful approach, I created approximately 25 small painted painscapes which tended to function as expressive interpretations of an imagined physical anatomy or internal pain associated with certain endometriosis symptoms. Eventually, as a result of the collaborative

exchanges (in Phase II) and the addition of a live audience (in Phase III), this painting practice evolved (see Chapter 5 for the full discussion and documentation).

‘The pain increased, I could sense “it” – meaning the all-consuming pain was already past the point of medication – but I needed to be in my own space and suffer alone without the embarrassment of being in a public space or God forbid, around other people. I slowly got my clothes on - shaking from the pain and the anxiety that the pain was overtaking my body. I washed up and waddled over to the table - probably clammy, and sweaty, and pale looking. I told my date I didn’t feel well and I’m pretty certain I was hunched over like the Hunchback of Notre Dame (that’s what I feel like, a monster) -- a common posture for me in times of pain. They asked if I was okay and I think tears uncontrollably started to drip out of my eyeballs. I managed to eek out the words to say “I get really, really bad periods.”’ (Personal Reflective Writing, March 2021)

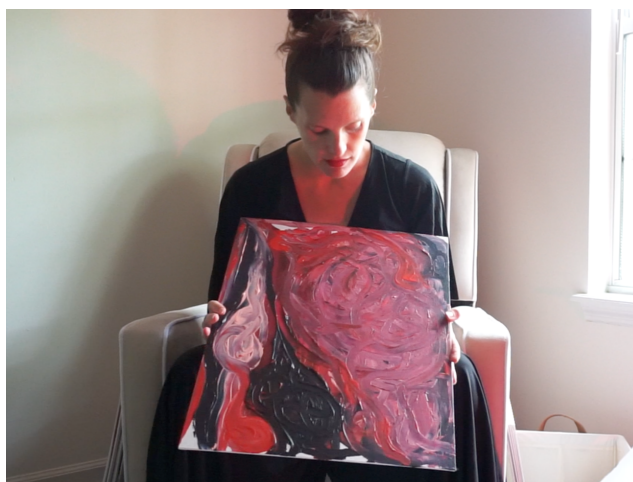


Figure 11. Phase I Visual Art Practice: Screenshot from Painting Series Documentation (May 2021)

[Link to Video Sharing Painting Portfolio](#)

Performance Art & Performance Art Films

Film Portfolio: <https://www.feelherpain.com/films.html>

Another pivotal modality that arose in Phase I is best characterised generally as performance art and more specifically as ‘yarn wrapping and unwrapping rituals’. These rituals combined repetitive

movement and embodied actions with visual art or the use of film as documentation and visual artefact. On a bi-weekly schedule, I wrapped and unwrapped various paintings with different coloured yarns which eventually extended to wrapping and unwrapping my body with red yarn. Exploiting these rituals allowed me to engage with the concepts of: revealing the invisible pain or often hidden grotesque dimensions of endometriosis; dressing the physical and emotional wounds/scars of endometriosis; and/or exploring feelings of identity or body constriction due to pain/disease incurability. This ritualistic practice elicited a spectrum of meanings and interpretations, which were subsequently reflected upon through embodied writing and incorporated in later creative processes.



Figure 12. Phase I Visual Art Practice:
Photograph of Painting (March 2021)

'Every time I mistakenly believe the battle is over, the disease shows up somehow, even in seemingly innocuous ways. I breathe differently when my phone app tells me my period is approaching. I see an ad for birth control on TV which includes women dancing and acting liberated and I feel overcome with grief and anger. In the anticipation of a debilitating pre-period week, I schedule my workouts accordingly. The heating pad is within reach at all times no matter how long it's been since I've writhed in pain. The infertility caused by endometriosis feels as painful as the lesions gripping my internal tissue and organs.'
(Personal Reflective Writing, March 2021)

In the beginning the ritual revolved around the previously noted paintings, commencing when the paint was fully dry. I wrapped the canvases meticulously and ritualistically with yarn aiming to eclipse or partially obscure the completed miniature painscapes, symbolically representing the concealment of women's pain and suffering. In general, the process of enveloping the canvas and thereby, covering the pain expression, was slow, methodical, meditative, and also, prolonged and tedious. Initially, the act of wrapping unfolded in a neat and organised manner seemingly serving as a subconscious endeavour to exert agency over pain or to reorient its narrative.



Figure 13. Phase I Visual Art Practice:
Photography of Paintings

'It's unnatural to stab yourself in the stomach with needles or to produce more than one egg in an ovary or to not have fallopian tubes. But there I was – confronting my own freakishly unnatural self in the mirror every morning and every night for a long period of time due to the infertility caused by endo. Each time I went to jab myself I would notice the little tiny scars on my belly which have been reopened surgery after surgery out of convenience for the surgeon and to aesthetically hide the repeated internal onslaught... They aren't ugly enough to show the ugly I have gone through and continue to go through.' (Personal Reflective Writing, March 2021)

The wrapping or unwrapping of yarn around the canvas transformed into the wrapping or unwrapping of yarn around my pregnant body. Wrapping and unwrapping my pregnant belly, where scars

congregate, accentuated the juxtaposition, irony, and contradiction inherent in Phase I of this research. Interestingly, these rituals document a unique moment of respite within the bodily domain where much of my pain originates. The yarn, in its enfolding, aids in redirecting attention to my endo-afflicted body into a site of rebirth, creation, growth, and beauty. Yet as previously addressed, even in its physical absence, pain persists as a ghostly spectre; hence, insinuating the crimson yarn simultaneously serves as a poignant memorial to the anguish that predated and persists beyond my son's birth. The filmed ritual assumed the mantle of a visual memento, a stark reminder of the pain that lingers in the annals of my corporeal history and prospective future.

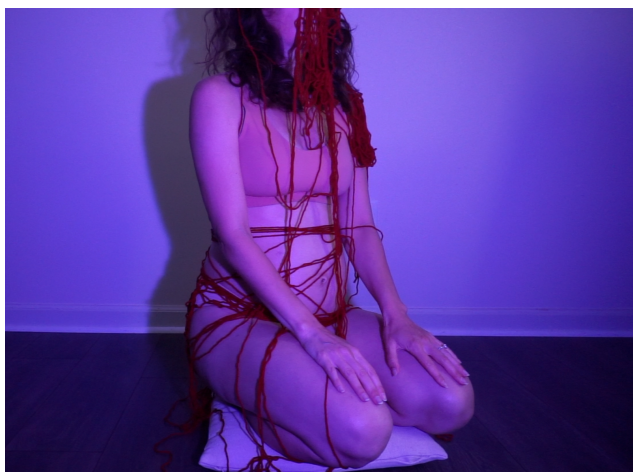


Figure 14. Phase I Practice: Screenshot from Wrapping Performance Art Ritual Documentation (March 2021)

'Each time I filled the IVF syringes and stuck myself in the stomach, I was reminded of my body's shortcomings. During the ultrasound scans, having become so familiar with the pelvic anatomy, I plainly saw and still see the sites of destruction. Every blood draw I undergo I think about how many veins I have had blown out over the course of my medical care. It's ugly. It's ugly how much energy and self control I exert trying to try and stay healthy and strong. I am tired. I am tired of the invisible monsters that swim in my bloodstream and cause my body to turn on itself. I am tired of the pity and the antipathy, both... I remember when I pushed the maximum dose of the hormone injection into my belly I thought about how I would never have known the breathtaking feeling of surprise from becoming pregnant naturally without needles and mental, physical, and spiritual depletion. The burden of this and the grief I feel around

this is inexplicable even to my husband.
 (Personal Reflective Writing, April 2021)

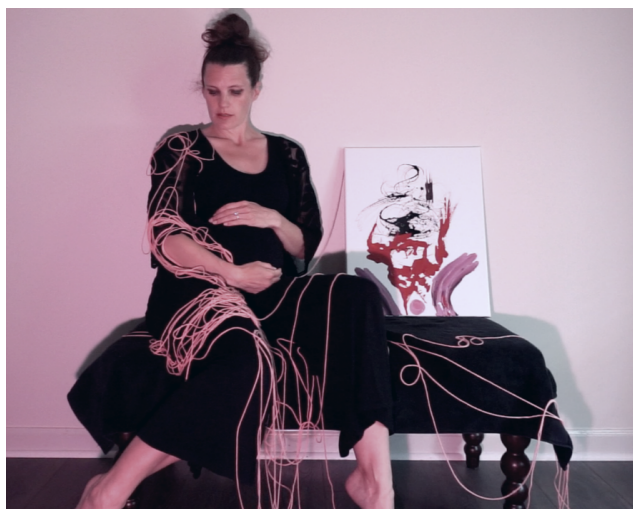


Figure 15. Phase I Practice: Screenshot from Wrapping Performance Art Ritual Documentation (April 2021)

Wrapping or unwrapping the body instead of the paintings heralded a shift towards a more restless energy, imbued with heightened expressiveness and gestural dynamism perhaps more accurately capturing the essence of a chaos narrative (refer to Chapter 1's narrative medicine discussion). Directing the yarn to my pelvis and specifically my uterus, I felt attuned, with heightened awareness, to the places of my body that have been subjected to surgical incisions, subsequent suturing, and post-operative dressing. Relatedly, the yarn directed presence to the spaces of my body impacted by repetitive scalding from constant re-application of heating pads during episodes of agonising menstruation, ovulation, or any interstitial times between. In the midst of wrapping my body, I became conscious of my embodied attempt to contain or bind my body with the yarn echoing a pursuit of control or agency. At times, when enveloped with care, the yarn seemed akin to a shield or armour, perhaps reminiscent of scar tissue, offering protection against external forces. Yet, there were moments when the yarn embodied the affliction itself, an unwelcome intruder breaching the sanctuary of my being and disrupting my space and time.

'Our first transfer failed and it was devastating. The doctor called 10 days after with my blood test results saying "Oh Kate I wish I was calling with better news." I was in a dark place feeling like my body had yet again let me down and betrayed me. I asked why he thought it failed and he really didn't know. "Maybe bad luck?" A constant feeling in my life with my body –No luck or bad luck. That night we stopped the painful intramuscular progesterone shots and picked up sushi and beer and just drowned in

our sorrow. The embryo had been female and most likely the only chance I had of having a daughter. So we grieved for the baby, and we mourned not having a daughter....I still mourn for this.’ (Personal Reflective Writing, April 2021)

Eventually, I executed these rituals as performances (albeit private) and filmed this process. In some cases, if I chose to edit the material, the filmed documentations became significant artistic outcomes in addition to procedural records. In these filmed performative rituals, which incorporated spoken poetry (and dialogic excerpts in Phase II) as a sound-score, I perpetuated the yarn wrapping or unwrapping action in conjunction with virtuosic dancing, gesturing, or embodied forms reminiscent of mimesis. Similar to the movement meditations described above, the authentic embodiments juxtaposed with the performativity cultivated through the stylised nature of the filmed rituals, again evoked a sense of ‘undecidability’ (Duggan 2012: 74), where truths, narratives, and abstractions merge - particularly in Phase II.



Figure 16. Phase I Practice: Screenshot from Wrapping Performance Art Ritual Documentation (April 2021)

‘Turns out both my tubes had to be removed because they were covered inside and out with endometriosis and scar tissue damage... The doctor also found more endometriosis lesions around my pelvis, on my uterus, and I think on some peripheral organ areas... Days and weeks later, even though I was of course sore and

healing from the surgery, I noticed my pelvis wasn't aching when I walked anymore—I hadn't even realised the tubes were causing me so much pain. That's what this disease does to you. You forget what it feels like to not be in pain. After about a month of healing, the IVF doctor said we could try again with a new transfer process. Miraculously, it worked.' (Personal Reflective Writing, April 2021)

In contrast to other modalities, I systematically reviewed and analysed these films, constituting a ritual in itself. Through iterative observation, I distilled rhythms, energies, postures, gestures, and essences that appeared to evoke and move me. Furthermore, by ultimately sharing film-work with collaborators, I discerned which performative elements felt most empowering and genuine for them, subsequently integrating these components into the final creative phase. As these particular painscape practices progressed, I expanded beyond yarn to include other materials such as masks and costumes. At times, the yarn was abandoned, while in other instances, it retained its role as the focal point. The embodiments and resultant imagery yielded a plethora of interpretations, some of which were dissected through written reflection, while others fuelled the methodologies or the ongoing creative collaborations, as expounded upon in the previous and the subsequent chapter, respectively. Ultimately, the utilisation of these materials can be viewed not only as a way to conceal or reveal pain, but also as a means to explore other aspects of identity in relation to endometriosis around gender and sexuality. The connection of these actions and materials to the expression and representation of marginalised (female pain) experiences will be unpacked later in this chapter.

Embodied Writing

As conveyed in the introduction to this thesis, an overarching aim was to authentically communicate the suppressed suffering of women to a wider audience, compelling me to actively witness, validate, and dignify endo narratives on a palpable narrative plane. To actualise this objective and to shed further light on the multifaceted dimensions of living with endo, I incorporated an embodied writing practice.¹² Esteemed psychologist and somatic scholar Dr. Rosemarie Anderson conceptualises embodied writing as a process that 'brings the finely textured experience of the body to the art of writing' seeking to articulate human experiences from within while intertwining our senses with the broader world. In her formulation, embodied writing strives to 'let the body speak' (Anderson 2001: 83).

¹²In addition to Dr. Anderson, feminist scholars have played a crucial role in advancing the discourse on embodied writing. Feminist writers such as bell hooks (1994) and Gloria Anzaldúa (1987) have explored the intersections of identity, embodiment, and writing, offering valuable insights into how personal experiences can be translated into written expression. Similarly, disability scholars like Tobin Siebers (2008) and Rosemarie Garland-Thomson (1997) have examined the relationship between disability, embodiment, and language, shedding light on the ways in which writing can challenge and disrupt dominant narratives about the body.

One century and a half or so ago
My soul's shell died
During childbirth.
I must have tried
To hold on;
To hold the baby.
But my womb
Shattered and bled out.
Murdering my possibility
Of motherhood.
My spirit grieves—still.
The grief poisons
Still.

In another era,
I was royal.
My only purpose —
Bring forth heirs.
I failed 10 times.
My insides were
Rotten.
I prayed for forgiveness.
Dark ugly circles,
Blackness,
Under and inside my eyes.
Fatigued from sadness.
In the recesses
Of my now subconscious
I remember the tears.
In fact, I can't forget.
My body won't allow it.
Not yet.

Beginning in Phase I, but developing over the course of the entire research journey, the more art I created, the more words seemed available for articulating pain — written, spoken, and performed. In this sense, as with the other modalities, this research's embodied written practice pushed to capture the multifacetedness of endometriosis experiences by truly using pain as material and compass. Embodied writing took on diverse forms and occurred regularly alongside the artistic modalities and as a painscape pathway in and of itself. While the critical theorising presented in this thesis constitutes one manifestation of written exploration, a significant portion materialised as autobiographical narrative testimonials and reflective writing (see the discussion around autobiography first mentioned

in Chapter 1). These writings serve to recount, process, or memorialise pain memories, endo experiences, methodologies, art-making processes, and collaborative exchanges.

*The other former life
Revealed to me,
Through suffering,
Happened in ancient Italy.
I lived under the shadow
Of a sleepy volcano
As it slowly awoke
From a long slumber.
I ran like the wind.
Hysterical with anxiety.
I gathered my babies
In my arms.*

*Afraid to lose them.
Panic consumed me.
But the other villagers
Sauntered calmly.
No need for alarm.
Ultimately after days of worry,
Nothing but some hot ash
Clogged my pores.
I didn't lose my children
But, I did lose my peace.
I guess I am still trying to find it.*

Crucially, poetry emerged as a prominent form of expression, as discussed below and interspersed throughout. My writing delved into the intricacies of IVF cycles, surgeries, recoveries, and vivid pain traumas endured — mine, hers, ours. I arranged words to convey embodied memories haunting the mind, body, and spirit. At times the writing served as content or material for the direction of artistic pathways. Frequently, sections of writing or poetry were shared with collaborators as a way to invite feedback or initiate new directions in dialogue.

*Past lives
Haunt my body.
Deep, deep down
My pelvis swells.
Turmoil manifests
Into sharp moments
Of toxic torment.
Teeth clenched,*

*I bear the fear
And deep rooted shame.
I listen to it,
But I no longer feed it.
This life will be recalled
Differently.
(Poem, 2021)*



Figure 17. Phase I Practice: Poetry Painting
(April 2021)

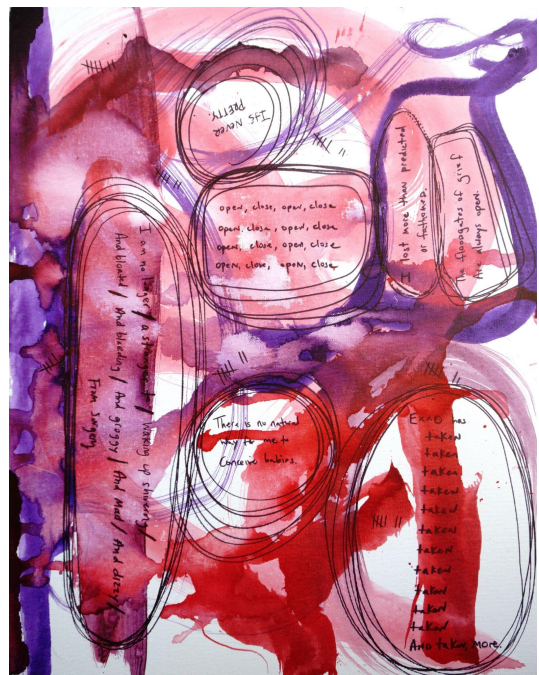


Figure 18. Phase I Practice: Poetry Painting
(April 2021)

The Emerging Themes

As mentioned in the beginning of this chapter, it becomes clear that the above processes mobilise characteristics of an improvisational presence mentioned in Chapter 2 in association with navigating endo's experiences of interruption and disorientation. For example, embodying adaptability allowed me to respond flexibly to the demands of my condition in order to create in and out of pain. Inviting a reverence for the unknown fostered curiosity and openness to new modalities and unexpected experimentations. Embracing heightened awareness and intuition encouraged mind-body synergy and self-reflection. Connecting with my somatic consciousness to pain and embodied memories emphasised the importance of listening to and honouring the body's wisdom.

In this section, through a distinctly feminist and crip lens, I reflect upon the preliminary conceptual and aesthetic trends arising from improvisational strategies. In particular, I highlight images, actions, or expressions in the previously described practices to demonstrate the ways in which they surfaced. These reflections not only reveal the endo-centric research practice as a feminist crip performance practice, but also illuminate embodied agency and, relatedly, time as well as in/visibility — both in the sense of externalising hidden internal experiences and expressing invisible voices and bodies — as thematic threads that were increasingly cultivated in this project's development and the realisation of netherness.

Embodied Agency

Discovering a sense of embodied agency while moving with and working with pain as material is documented in dance artists with chronic pain (Meehan 2003). Likewise, this project's methods enabled me to experience a profound connection between endo pain expression and accessing agency. For instance, calibrating to bodily sensations and pain memories empowered me to embrace the wisdom of my non-normative body which simultaneously led to self-expression, acceptance, liberation and vitally, the creation of practices and works that addressed the complexities of endo-pain with a newfound clarity and value.

Aligning with the recent 'phenomenological shift in disability choreography' (Sandahl 2019), my improvisational approach mirrors the methodology of crip artists who leverage their unique disability experiences to reshape their choreographic narratives. Despite my body's outward appearance not conforming to a typical image of disability, the embodied actions within my creative practice bear the consequences, ambiguities, and tensions of an internal disease. Attending specifically to the articulation of pain, the boundaries of disability choreography are expanded, echoing the perspectives of Sarah Hopfinger who was first mentioned in Chapter 1. In delineating a 'crip performance practice' Hopfinger (2021) emphasises the importance of an affirmative approach, not as a means of denying the challenges of the chronic pain experience, but as a way of (re)claiming the chronic pain body as valid and knowledgeable. Within this framework, the complexities of chronic pain are respected and drawn upon (Hopfinger 2021: 125-126).

In this phase, as the parallels between my improvisations and crip performance practices became clear, I more naturally embraced crip stances on normalcy. This not only initiated shifts in my artistic practice, but also supported the reclamation and channelling of my own crip identity (Sandahl 2003, 2012). Importantly, these efforts were enacted through Robert McRuer's notion of 'critically crip' which argues that any claim to crip be mounted with intentional criticality (2006). Locating my artistic practice within the realm of crip art illuminated ways agency might be recovered for endo bodies and identities. In particular, given my expertise and the explicit role of the body, dance and performance provided a potent platform for such.

Embodying and emphasising the uniqueness of certain postures or trajectories resulting from an endo body's suffering or internalised trauma allowed for niche body language and mediations with space to emerge. Some of the most recurring and compelling trends originated in the aforementioned movement meditation research. These included: a non-vertical/grounded body, a body doubled over, a body in foetal position, or a body in a bracing position. Reframed as a crip performance practice, these expressions were welcomed as novel and indicative of robust interiorities rather than dismissed as limited or tedious.

For instance, through repeated analysis of recorded improvisations and immersive engagement with the recurring embodiments mentioned previously, I came to the realisation that my endo experiences often prompted my body to inhabit non-vertical spaces. This observation elicited contemplation on the significance of this non-verticality, or horizontality, in the pursuit of embodied agency. Such reflections encouraged an exploration of scholarly discourse surrounding the performative action and metaphors surrounding falling. These discussions appear to share a common divergence from conventional upward orientations, instead inviting perspectives that are more directed towards celebrating the ground (Albright 2018: 47). While my personal illness experiences of falling have been limited to instances where pain forced me to lose consciousness, exploring the concept of falling and its performative and embodied implications becomes a necessary segue into analysing how a body in pain might embody agency.

In the field of western contemporary dance and improvisation, falling with skill, without injury, and for maximum 'spectacular impact' is considered a necessity and an essential component of movement vocabulary (Claid 2013: 80). Unlike most ballet traditions, contemporary dance, and movement improvisation invite floor-work and downward trajectories as beautiful and requisite physicalities. The visible technique and command of the body required in an intentional succumb to gravity becomes exciting to witness as an audience member and equally thrilling to master or execute as a dancer. However, beyond this performative embodiment, personal and cultural meaning can be ascribed to various downward body postures when the stages of falling are scrutinised with focus and attention. Subsequent associations of vulnerability/disease or poise/able-bodiedness can be made.

For example, in her artistic research practice, psychotherapist and dance artist Emilyn Claid considers the four embodiments of falling as defined by: face-to-face, stooping, kneeling and lying (Claid 2013)

— notably, these embodiments are all extremely visible within my endo-centred practice. Claid acts as a dynamic witness to a male dancer named ‘Kudlip’ as he intentionally and slowly falls in front of her. Kudlip and she both articulate observations as the fall progresses through four referenced stages of falling starting with being face-to-face and ending with the dancer lying horizontally on the ground. Claid reads his slumping body as faltering and her reflections resonate with how I witness and personally embody endometriosis pain as she declares, ‘Kuldip’s body posture of stooping affects me kinaesthetically. I feel a social responsibility to fix this discomfort — for us both’ (Claid, 2013: 76). In her own body she seems to feel haunted by the pursuit of verticality as she writes, ‘Kuldip’s slumping evokes my shame — a persistent *ghost* from my training as a ballet dancer’ (Claid 2013: 78). Witnessing his fall, where he falters from a place of verticality to a closer positioning to the floor, Claid herself feels discomfort from his supposed shame and collapse. Even though the dancer is performing a slow motion fall without risk of injury and without pain as an origin, a lurking sense of aloneness, isolation, and instability emits from the limbo body as it slumps and stoops — not quite steady in the vertical and not quite horizontal yet (Claid 2013: 78).

Claid discusses this position and the eventual fall in depth, but fails to ask questions relevant to a crip perspective or identity which ultimately become central to a netherness praxis. The performance of a fall or performatively posturing extreme pain is vastly different from falling down or over due to pain or falling down into pain. What if the dancer/body was caught in this slumped position never executing the full fall and never finding support from the ground? What if the stooped position is not from an intentionally designed choreographic task, but is caused by illness, disease, or disability? To me, as she describes the dancer finding his way to kneeling and then eventually lying on the ground, I feel some relief for both of them. The fall has been properly executed, the task is complete. His body can pause and then find a way back up to standing upright, to being face to face with another person. However, this swift return to verticality is not a possibility for all bodies. Sometimes, being stooped over, slumped, hunched, or caught in a liminal place between upward and downward is an endo body’s unrelenting duet with gravity and with pain. Perhaps, as my research ultimately demonstrates, intentionally participating in and engaging with these (im)mobilities creates opportunities for innovation.

These embodiments which were ‘necessitated through living with chronic pain’ can be viewed as crippled manifestations of resilience (Hopfinger 2021: 124). Resilience or ‘crip resilience’ in this case refers to not pushing through pain or hiding pain for the sake of an aesthetic of ableism, normalcy, or idealised notions of beauty (Hopfinger 2021). Resilience defined from this more affirmative perspective emerges through creating with and through ‘the expertise of an [impaired] body to move in unique and creative ways’ (Hopfinger 2021: 125). In this sense, the movement and artistic research become both the foundation of inquiry and the mode of inquiry. In celebrating the body’s differences through creative expression, pain was both articulated and honoured as an experience garnering compassion, empathy, and curiosity.

Relevant to this discussion, it is worth emphasising that unique physical embodiments in certain months of pregnancy generated new ways of using hips, pelvis, back, and core muscles that differed from my non-pregnant movement practice. In actuality, being pregnant is irrefutably another female experience of interruption garnering a different level of attunement and attention to the simultaneous embodiment of femininity amid discomfort and physical interruptions/restriction. Frequently, these movement improvisations elicited frustration: I felt ill-equipped in moving my body as eloquently as in the months preceding pregnancy. However, my attempts to embrace these perceived obstacles as enriching my practice and exploration of pain exemplifies a pathway towards crip resilience.

By centring the body as the locus of authority, other artists with endo and other invisible pain might also experience renewed ownership of their narratives; reclamation of power and assertion of their identities in a society that often seeks to marginalise or erase their experiences. This link between pain expression and a reignited sense of agency, initially reflected upon in this phase, led me to consider the resonance between the research approach and a crip performance practice — inviting exploration of crip culture and identity. As such, ‘embodied agency’ ultimately develops as an important conceptual thread that transforms the aesthetic outcomes of the practice (see Chapter 4 and 5 for further developments) and provides a foundation for deepening the applications of netherness in relation to a crip arts practice (see Chapter 6 and Conclusion).

Time

Next, the art-making in this phase initiated an exploration of non-traditional temporalities and the disruption of time; explorations which expanded throughout the research. The ability to navigate time — whether it involves adapting to the unpredictable rhythms of endo pain; recouping creativity amidst interruptive gaps or other temporal constraints; or resisting societal pressures to conform to normative temporalities — can be viewed as an iteration of embodied agency. Yet while inherently intertwined with broader discussions on agency, the navigation of time and exploration of temporality warrant dedicated discussion due to their profound implications for lived experiences and expressions of identity.

As an example, in this research I worked more intentionally within the currents of spontaneity and urgency by creating art in quick-fire bursts of action in various *windows of opportunity*. This approach organically evolved from my history of perpetually adapting to the chaos of pain. This burst action pattern is a form of anticipatory scheduling characteristic of some versions of crip time and as such, can be viewed as a component of my personal manifestation of crip art-making (refer to crip time discussion in Chapter 2). Notably, though I was not actively in pain related to endometriosis throughout this early stage of the research journey, I was pregnant. Likewise, in the research phases to be discussed, I was either experiencing time as postpartum and/or nurturing an infant or young child. These maternal interruptions sustained the art-making as bursts of creative exploration that had previously developed as a result of pain experiences. Additionally, in the middle of the research,

endometriosis symptoms returned and a cancelled IVF cycle became a savage reminder of my body's interior wreckage as the anticipatory scheduling continued.

Again I turn to Hopfinger who reveals a similar approach in art-making. Hopfinger describes the impact that chronic pain has had on her writing and choreographic practices. Particularly, akin to the bursts characteristic of my artistic practice, she characterises her writing practice as 'short stints, as I am unable to sit or stand still for more than one hour at a time' (Hopfinger 2021: 123). She elaborates on her experiences indicating how the 'disruptions from muscle pain, stiffness, inflammation, aches, nerve pain, and so on' determine not only her thinking, articulation of ideas, but also the punctuated nature of her daily creative practices (Hopfinger 2021: 123). For example, the reference article itself is structured in a 'punctuated form, moving between transcribed dialogue..., critical discussions, video footage, personal writing, choreography descriptions, and performance texts' (Hopfinger 2021:124). Her performance, research, and writing practice are a dynamic response to her body's fluctuating and chronic needs and demands, and consequently, the outcomes of such also are shaped by this. Comparable to my experience, Hopfinger's body's pain and the consequent negotiations with time or space is written into her research. Indeed, working with the interruptions of our bodies in artistic practice and research, Hopfinger and I both, as writer Lara Birk describes it, 'acknowledge the embodied nature of knowledge production' (2013: 391).

Beyond thinking only of the windows of opportunity and the overarching conceptual integration of crip time, I reflected on how I engaged with the 'gaps' or as articulated in Chapter 2, the moments in time born from disorientation or interruption. Spending creative time in the 'gaps' forced me to modify my engagement with temporality within the artwork itself. For instance, I observed how pain and invisible disability dictated variations in pace and rhythm in my movement practice. Namely, the dynamics that recurrently manifested included: stillness, deceleration, or rhythmic repetition. These embodied temporalities reveal how trauma and/or pain changed how the improvising/dancing body required me to participate in certain energetic qualities. In moments of disorientation or interruption, whether I am experiencing menstrual pain or other physical sensations like migraines; surgery and surgical recuperation; or an IVF cycle, my body physically demands a certain connection to time and space (a common experience for the five other collaborators as well which will be highlighted in Chapter 4). These qualitative shifts occurred especially in downward trajectories or lower, horizontal positions which will be elaborated upon below.

The aforementioned vocabularies and the energy variations characterised by the body being slumped over or horizontal, moving slowly, or not at all, might be traditionally perceived as antithesis to the norms of conventional Western dance practices (i.e. ballet). However, as will be expanded upon throughout the thesis, these expressions can serve as significant choreographic tools, foregrounding a 'practice of care and resilience' within a crip performance framework (Hopfinger 2021: 125). The development of such practices is examined in Chapter 5 and further explored in Chapter 6 in conjunction with a

netherness reorientation towards what Kafer terms as a crip ‘elsewhere’ (referenced in Chapter 2, Kafer 2013: 24).

The unfiltered and emotionally raw movement meditations also served as seeds for contemplating time in a way reminiscent of Kafer’s ‘embodied dualness’ mentioned in Chapter 2. Yet in these explorations instead of just conceiving of my body in the present and the future, I engaged with my pain and body in the present and the past. This kind of embodied temporality might be understood through the lens of trauma. To again quote Duggan: ‘Trauma can be seen to rehearse, repeat, and re-present itself in performed “ghosts” that haunt the sufferer, and to require “acting out” in order to “work through”...’ (2012:5). Historian and trauma theorist Dominic LaCapra also refers to this sense of trauma sufferers having a tendency to ‘relive the past, to be haunted by ghosts or even to exist in the present as if one were still in the past, with no distance from it’ (LaCapra 2001: 142–3).

This expansion across time, through the lens of memory, is also touched upon in a different writing piece from Albright (dance scholar referenced in Chapter 2). Extending deeper into her discussion of improvisation, she engages with a celebration of the downward and writes about a notion of ‘dwelling’ as a ‘space where time enters to slow down’ (Albright 2018: 102) in connection to memory and improvisation. In this creative practice, remembering or dwelling on past pain, my body called forth what was no longer felt or visible, registering the traces of the past in my tissue, blood, muscles, bones. Dwelling in these memories through movement, writing, and visual art explorations, transported me to another time and space; pulling me ‘back and down into the dark below the earth’ (Albright 2018: 106). Albright suggests, such memories, which inhabit our bodies and connect time with space, are best followed, not forced (2018:106). Attending to the suspensions inside our breathing can support an improvisational dwelling on the pain that haunts the body across time. I experienced this most frequently in the painting and yarn wrapping practices. For instance, it was unclear whether the yarn represented the past, present, or future. Was the yarn representative of the temporal process of healing and scarring? Was it present pain or lingering grief around pain being externalised? The pervasive way in which endometriosis ‘haunts’ our bodies across time, through memories and even within moments of non-pain, contributes significantly to the overall ambience of liminality eventually captured in the realm of netherness (see Chapter 6).

As a dimension of lived experience, time profoundly influences how individuals perceive, interpret, and respond to their environments. As discussed in Chapter 2, endo and other female lived-body experiences can significantly alter our perception and experience of time. The disruption in time caused by pain — whether cyclical, unpredictable, acute, or chronic — often impacts our sense of productivity and relationship to the past and future. As such, this practice increasingly awakens, expands, and questions the experience and understanding of pain by using time as a thematic thread for critically dismantling ‘internalised able-bodied assumptions’ (Hopfinger 2021: 128-129).

Expression and Representation of the 'Invisible'

This research praxis also compelled me to confront other normalised or idealised conceptions around beauty, femininity, sexuality, wellness, and able-bodiedness — societal norms which contribute to the invisibility of difference or 'otherness'. For example, as discussed in Chapter 2 embracing an improvisational presence allows the body and identity to more attentively converse 'with ambiguity, uncertainty, potentiality, and choice' (McDowall 2019). Executing this in dialogue with my body's invisible pain, I discovered a fertile ground for the expression of the complexities of endo experiences and the representation of oppressed bodyminds — regardless of how monstrous, grotesque, chaotic, subversive, paradoxical, or abject the experiences might be. In this way, visibility (or lack thereof) — became an increasingly valuable theme in the painscape practice, first emerging in this phase.

In particular, my engagement with writing and visual storytelling through performance/visual art practices produced some interesting insights around these topics. To begin with, as a form of creative expression and experimentation requiring less physical demand, writing offered a versatile outlet for artistic exploration especially when grappling with debilitating pain or immobility. Writing has always assumed an integral role in my artistic journey, but it is particularly essential because it is a means of expression irrespective of my body's immediate engagement with endometriosis symptoms or with concurrent circumstances such as IVF cycles. In this sense, embodied writing practices can be utilised as a way to bolster the efforts to create a painscape performance/movement practice.

That being said, at the outset, I harboured a reluctance toward the utilisation of verbal and written language in my artistic research pursuits. However, as the process of art-making unfolded, it became apparent that the exclusion of all words from a painscape — which intends to convey individual and collective pain narratives — resulted in the loss of powerful metaphors and storytelling embedded in the experiences of those grappling with pain. As a result, despite the argument posited by Elaine Scarry that pain relegates words to obsolescence, this research ultimately demonstrated that pain, coupled with pain-informed art, can serve as a conduit for the generation of new language and the inspiration of innovative expressions.

I discovered profound significance in the amalgamation, abstraction, or interpretation of words derived from personal or collaborative pain narratives, in conjunction with or through movement expression. In using pain as the point of origin, the written aspect of this research amplifies and honours my endo body, her endo body, and our endo bodies — an amplification particularly pivotal in the aftermath of post-medical encounters (Kuppers 2008:141). Additionally, the writing and spoken word painscapes that emerged accentuated the political activism and inclusivity research aims. Speaking or writing about the body, particularly a crip female body, breaks socio-cultural taboos of silence and secrecy around the feminine experience (DasGupta & Hurst 2007: 15).

As I explored the role of words in this project, engaging in poetry and experimenting with 'the poetics of becoming visible' (Kuppers & Marcus 2008: 67) emerged as crucial for honouring our individual

and collective experiences. Poetry proved instrumental in ensuring that each body's story was undeniably acknowledged, particularly for collaborators who were unable to directly participate in my creative expression or their own artistic process. The liberating and empowering form of poetry allowed ample space for the body's voice to be heard, seen, and felt.

Specifically, Petra Kuppers's writing around and through crip poetry, as briefly touched upon in Chapter 1, enlightened the development of ideas and perspectives in this project. The inclusion of 'scars, pain, wounds, and the places they are born' in Kuppers's crip poetry (2008: 141) and her analysis of the works of other crip writers, reveals the whole of crip culture as a safe haven for those of us with endometriosis and provided courage for locating this research's writing in the domain of crip poetry. As such, the writing was born directly from the body and flesh; bones, organs, lesions, adhesions, scar tissue, or menstrual blood became visible and indeed, tactile through the viscosity of crip poetry. Words seem to grow wings to fly above traditional constraints of language; additionally inspiring intersections between poetry and the other painscape modalities described above.

In particular, a recurring theme and site of inquiry in Kuppers's analytical writing and poetry is the scar. She uses the embodied sign of the scar to 'trace ambivalences, shifting meaning and the transformation of personal material into poetic labour' (Kuppers 2008: 141). As someone with several scars from endometriosis surgeries, I concur with her perception of scars and scar poetry not as sites of negativity nor loss nor shallow celebration either, but as perhaps, generative places for sharing pain, tracing time, remembering resilience, and forming connections. Gradually, throughout the research, the scar — functioning as 'experience, image, and embodied trope' — evolved into another profound source of embodied agency and inspiration for the manifestation of netherness (Kuppers 2007:1). Ultimately, as a result of embodied writing processes, a collection of six complete poems materialised directly inspired by each woman involved in this project (see Chapter 5 for poetry portfolio and discussion).

Similar to these creative writing practices, the performance/visual art explorations and films stand out for elucidating the potent portrayal and exploration of the multifaceted nature of an endo identity, providing support for other endo warriors in their own journeys of identity exploration and healing. As I attuned to the multidimensionality inherent in my crip identity, an endo 'split self' emerged somatically, intuitively, and unpredictably. This 'split self' or perhaps dissonant state of being — wherein the grotesque coexists with the beautiful (see Chapter 6); the broken dances with the whole; the past or future merges with present; and the body embraces both darkness and light — solidified more deeply in the collaborative exchanges (as described in Chapter 4).

Conclusion: The Birth of a Research Methodology and Practice

Honouring the nuances and complexities of my endo experiences necessitated artistic experimentations which championed adaptability, the unknown and invisible, somatic awareness, and an overall improvisational presence. These endo-informed practices, introduced in this chapter,

included movement meditations, body-painting, performance/visual art rituals, and creative writing. Though exploratory in this phase, they served as foundational strategies for inviting endo pain into the creative process. As the research progressed, these modalities expanded and hybridised, deepening the disruption of conventional understandings of pain and identity, forging new pathways of understanding and expression. In general, Phase I initiated an embodied research landscape ‘where her body finds (and is) her voice’ (Bacon, 2010: 73).

The endo-centric and improvisational approach to painscaping led to the emergence of specific conceptual and artistic themes. These thematic trends can be summarised as experiential investigations around endo-painscapes and embodied agency; endo-painscapes and time; and endo-painscapes and in/visibility. Some of the standout ideas which gain traction and fundamentally steer the research journey include: crip explorations or deconstructions around identity, pain, and resilience; the externalisation of internalised experiences, sensations, and anatomies; and the concealment or recovery of pain memories, chaos narratives, wounds, and scars. As a whole, this thematic content forges a deep sense of dissonance or liminality in meaning and aesthetic, ultimately contributing to my expansion of netherness (see Chapter 6 for this discussion).

Likewise, as I navigated the complexities of living with endometriosis, my arts practice served as both a mirror and a lens, reflecting and deepening the research’s methodology as a convergence of art, theory, and lived experiences. Improvisation implicitly empowered a creative practice to confront interruption, disorientation, and invisibility. A feminist perspective infused the improvisational practice with a critical edge, challenging societal norms and interrogating the gendered dimensions of pain and illness. The emerging modalities and outcomes confront the invisibility of women’s bodies, reclaiming agency and autonomy in the face of patriarchal systems that seek to marginalise and silence our bodies and experiences. Similarly, drawing upon crip identity, specific aspects of the arts practice amplified marginalised narratives and challenged ableist assumptions about what it means to live and create with chronic illness/pain.

At the conclusion of Phase I, I gave birth to my son and took a three-month maternity leave. This transitional time offered a reflective moment of pause and introduced new layers of understanding into female experiences of interruption. This short gap preceded perhaps the most central aspect of the research: the integration of other women’s pain experiences in the art-making practice or Phase II.

CHAPTER 4: PHASE II: PAINSCAPE RESEARCH PRACTICE — COLLABORATIVE EXCHANGES

Introduction: The Postpartum Period

Following my son's birth and maternity leave, which introduced new personal dimensions of interruption, the research journey recommenced, and Phase II unfurled. In this phase (September 2021-March 2023), my artistic process and how I have understood my role as artist or artist researcher was profoundly transformed through the addition of one-on-one exchanges with Jessie, Toby, Chelsea, Mei, and Danielle, all of whom have endometriosis. With these collaborators, I further developed the methodological concepts, practices, and values of the research. My first-hand understanding and intimate experience with endometriosis drove this expansion, rooted in a profound sense of empathy, ethics, and solidarity. Significantly, as this chapter substantiates, these intimate collaborations granted me the opportunity to speak both directly and metaphorically, to, through, and about my own crip bodymind, in and out of pain.

In this chapter's first section, the general methods and ethical considerations involved with the collaborators are outlined. Here, it becomes clear that the exchanges, or 'duets' as I frequently refer to them, emerge as: interpersonal spaces of shared experience and support; a way to gather stories and experiences from other women; and a feedback and iterative refining process for my creative praxis. This discussion reveals the role of collaboration in inviting meaningful dialogue, authentic interactions, and realising a feminist/crip painscape practice.

Next, in the ensuing writing, delineated by each of the collaborators' first names, the interactions with each woman are illuminated through a more personal writing style accentuating the increasing reflexivity and intimacy of the praxis. The distinct subsections attempt to loosely pinpoint moments in the pain narratives, exchanges, and art-making which left a discernible imprint on the development and creative realisations of *Nether Space(s)* (the processes and outcomes of which are pinpointed in Chapter 5). The introduction of each woman follows the sequence of the initiation of the exchanges, while the subsequent chapter presents their resulting painscapes in the order of creation. Throughout the subsections, I integrate reflection and analysis, focusing in particular around the thematic threads of embodied agency, time, and the representation/expression of in/visibility introduced in Chapter 3.

In the third segment of this chapter, I delve deeper into themes like 'witnessing pain' and 'validation through visibility' which arose from these exchanges. I briefly dissect how these developments might correlate and intersect with the previously determined conceptual and aesthetic trends. In their dissemination it becomes increasingly clear that the forged research practices provide a framework for capturing and sharing endo stories and experiences.

The Duets

Ensuring rigorous ethical, legal, and professional standards, this research was conducted in accordance with the Middlesex University Research Ethics Review Framework.¹³ Prior to the start of Phase II, I obtained approval from the university review board, which ensured conformity with the university's codes of research practice. The ethical principles of this framework are reflected in the research's protection of personal data; consistent written consent before documenting or disseminating material; and verbal or written confirmation from collaborators regarding naming preferences in analysis or acknowledgment. Confidentiality was strictly maintained, with sensitive information securely stored and accessed only by me. While no conflicts of interest ultimately surfaced, I was prepared to proactively manage them if they arose. Of utmost importance, throughout the project, the well-being of participants (and myself) was prioritised, with measures in place to provide support if discussing female pain experiences caused distress. By adhering to the review board's protocols and guidelines for responsible research conduct, this study not only met, but exceeded the ethical standards expected in academic research. Moreover, upholding feminist and crip ethics of care ensured that the substance and values of this framework were embedded in the research methods.

Prospective collaborators were all located by word of mouth from September to November 2021. Prior to engaging in the duets, detailed information about the research, accompanied by visual representations of emerging artwork from Phase I, was provided to potential collaborators. Subsequent to the receipt of five signed consent forms, the scheduling of recorded Zoom sessions or in-person sessions, ensued. The intentionally small cohort¹⁴ facilitated flexibility and more extensive exchanges over the course of the project, deepening my relationship with each collaborator. Accordingly, this group size afforded me the opportunity for introspection and provided necessary distance from the vulnerable and intimate subject matter as needed.

As part of the on-boarding process, I explicitly clarified to collaborators that the research intentions were around the communication, initiation, and exploration of new dialogues specifically about endo pain and more broadly, female pain. It was crucial to convey that therapeutic outcomes or intentions of treatment/cure were not the objectives. Nonetheless, I anticipated that empowerment, validation, transformation, and catharsis might arise from our shared experiences and affective exchanges, as often seen in painscape and improvisational practices (discussed in Chapter 1, Tarr et al. 2018: 580). Indeed, as active participants in transforming our pain narratives into painscapes, both the collaborators and I experienced some or all of these participatory benefits. By establishing the ethical

¹³ I began my PhD at Middlesex University before transferring to Central Saint Martins. For more information regarding the Middlesex University Ethics Framework and Review Board: <https://unihub.mdx.ac.uk/study/spotlights/types/research-at-middlesex/research-ethics>

¹⁴ Although I anticipated working with ten collaborators, as the research unfolded, it became evident that the volume and depth of data generated in each creative session series per individual necessitated a scale back to five collaborators. This strategic adjustment was imperative to adequately honour and appreciate the unique embodiment and voice of each participant.

tone of the research with transparency and accessibility, each prospective collaborator made an informed decision regarding active participation in both the artistic process and the doctoral research.

Next, I consciously designed the exchanges to unfold as duets between myself and one other woman at a time, as a respectful and ethical means of acknowledging and witnessing an individual's pain experience. These one-on-one interactions manifested as an intimate series of Zoom or, where possible, in-person sessions. The programming logistics around the duets in and of itself validates and addresses the collaborators' individual experiences of endo pain — and its associated interruption, disorientation, invisibility, and unpredictability — by tapping into mutual tenets of crip time and improvisation like readiness, flexibility, and spontaneity. For instance, I directly expressed my commitment to accommodating scheduling changes and/or other kinds of modifications (like changing topics, concluding a session, or adopting alternative modes of dialogue) as a demonstration of my valuing their time, experiences, triggers, and inputs. Simultaneously, I openly indicated my own need for reciprocal flexibility, given my role as a new mother and my existence as an endo sufferer. Markedly, there was a deliberate avoidance of imposing pressure concerning the required number or duration of sessions. Instead, prioritising crip time, a flexible range of three to six sessions with a duration of 30 to 90 minutes per session, was offered.

Notably, beyond logistical aspects of the research, the creative bursts mentioned in Chapter 3 as an embodiment of crip time were also palpable in Phase II. However, as my creative work relied on both the collaborator *and* my own experience of interruptions and windows of opportunity, they were, perhaps, even more pronounced. For instance, sometimes I shared my work and received immediate feedback from collaborators promptly fuelling an iterative feedback loop and artistic unpacking. In these cases, the art-making gained momentum, inviting a different level of focus and attention. Other times, some collaborators were unable to provide feedback given certain circumstances or their presence was impacted by endo related experiences. For example, Chelsea had to undergo an unexpected endometriosis surgery and subsequently needed recovery time. Other scheduling adjustments happened as a result of collaborators or myself suffering abdominal or migraine pain, experiencing intense fatigue, or attending to family obligations. Ultimately, despite navigating such interruptions, I was able to 'hold the space' (a phrase coined by Plett 2020) for and with each creative collaborator for a minimum of four hours per individual.

Almost all sessions, whether in person or virtual, began with 10-30 minutes of unrelated 'small talk' and then transitioned to verbal exchanges centred on lived body experiences. Additionally, over the course of the collaborative duets, many of the painscape processes and artefacts disseminated in Chapter 3 were discussed, demonstrated, and/or presented. The fusion of light and casual conversation with vulnerable recollections and expressions of pain and disease seemed pivotal in deepening the level of authenticity and connection within our duets. I would ask each woman how she was feeling that day and confirm her desire to proceed. Based on her comfort level, I encouraged each woman to articulate and expound upon any significantly vivid pain experiences that emerged in her mind. I

acknowledged each collaborator's courage in sharing such personal experiences. Both the duet work and solo research inherently relied on these functional states of fluidity and ambiguity, reminiscent of what Albright refers to as necessary for self-preservation (see Chapter 2). The use of improvisation in both language and unfixed interactions fostered a space of connection and compassion, thereby enabling the expression and communication of otherwise personal and sensitive matters.

In addition to the revelations gained through verbal exchange, the duets offered opportunities to transcend the conventions of dialogue. Indeed, they evolved as creative, open-ended, and intuitive dialogic interactions, which felt more authentic and vital than conventional interviews or structured questionnaires. Likewise, I extended an invitation for each woman to participate in certain aspects of my creative process in a manner that felt comfortable and natural to them, either during or subsequent to our sessions (refer to the subsequent subsections for detailed insights into each collaborator's narrative and highlighted contributions). For instance, if the collaborator had a background in the arts, she might engage in her own artistic practice and share her work with me. The non-verbal discourse that arose outside the scheduled Zoom or in-person sessions made significant contributions to and elevated the collaborative interactions by providing alternative means of communication and connection. Some women communicated ideas or creative outputs through emails, videos, or even text messages. We engaged in discussions about their artistic explorations in relation to our dialogues, thereby mutually propelling our creative endeavours. This open design allowed each duet series to follow a distinctive trajectory, incorporating varying degrees of verbal and non-verbal/creative interactions.

Now, in more traditional research or therapeutic models, the researcher or therapist typically occupies a position of authority. Often, this can create a hierarchical structure that can result in a power imbalance and dynamic leaving participants or clients feeling less empowered to contribute fully or authentically. However, as evidenced in this project and for example, Deborah Padfield's work (<https://deborahpadfield.com/face2face-1>; Padfield 2011 referenced in Chapter 1), engaging participants as collaborators allows for the power dynamics to shift, inviting a more equitable exchange of ideas and experiences. As Padfield emphasises, this kind of co-creative exchange, where the boundaries of fine art are extended, leads to an aesthetic that is otherwise unattainable when working alone (Padfield 2002: 572). Through shared control of the creative act of art-making resulting in a negotiated aesthetic, instead of being on the passive receiving end of a medical/photographic gaze, pain sufferers discover a new agency in how their pain is communicated and visualised (Padfield 2002).

Furthermore, my dual role and perspective as both endo sufferer and artistic researcher allowed me to appreciate others' endurance and relate to their experiences, thereby relinquishing some of my power as a researcher and creating broader opportunities for connection and exchange (Adams & Jones 2011). Such an egalitarian approach aligns with the feminist/crip aim to dismantle conventional power

structures and challenge societal norms, establishing mutual respect and shared ownership of the process and outcomes.

While collaboration promotes the erosion of rigid hierarchies which might enable deeper openness, it necessitates careful consideration of ethical boundaries. Researchers must navigate the fine line between personal sharing that enriches the interaction and maintaining professional boundaries that ensure the integrity of the process. The appropriateness of sharing personal material varies depending on the context and the individuals involved; the nature of the study; and the relationship with collaborators dictate what level of personal sharing is beneficial and ethical.

For instance, in projects like this, where the researcher's personal experiences are integral to the study, sharing personal material can further cultivate trust and reciprocity leading to more nuanced knowledge, as individuals may feel more comfortable and validated in sharing their own experiences. With this in mind, and tapping into the autobiographical nature of this and painscapes research described in Chapter 1, I matched the collaborators' tone and level of disclosure by sharing my own endometriosis experiences. By revealing particularly in-depth personal details of my life, I demonstrated a willingness to be vulnerable and open with each collaborator. Shared vulnerability can deepen the connection between researcher and collaborator, enhancing the quality and depth of the 'data' collected. Regardless of the dialogic trajectory or the extent to which collaborators or I chose to divulge, their stories, emotions, and corresponding body language sparked creative breakthroughs, aligning with what creativity and improvisation researcher Keith Sawyer characterises as 'lots of little sparks of insight that occur as people respond to each other in dialogues' (Sawyer 2003).

As Phase II progressed, the solo and duet explorations seamlessly merged, reaching a point of inseparability and indistinctness. I utilised our dialogues, their words, and, in some cases, their non-verbal creative expressions, alongside my personal history with the disease, as interwoven inspiration, content, and material to shape, guide, and enact an embodied arts practice. I welcomed the collaborators into my creative world by sharing the ideas, pathways, processes, and artistic outcomes which ultimately had been inspired by, and intended as, respect for their and my pain. They provided feedback, and I incorporated their impressions, both verbal and body language, back into my creative process. This iterative loop is the first time I have so dynamically engaged with individuals outside of my creative circle when developing a new body of work.

Overall, the mental and physical toll of the exchanges — be it the intimate and potentially triggering content, various personal or endo-related interruptions, logistical challenges such as rescheduling, or the need for open-ended time and space to regroup and resume — could potentially hinder collaborative momentum. However, remaining responsive and attuned to the overall needs of the collaborators (and myself) felt necessary in this context and proved essential in fostering trust and embodying empathy. We adapted to each other's life circumstances and unconventional temporalities as a means of signalling respect, understanding, compassion, and solidarity. These foundational elements were crucial in cultivating trust, fostering the intimacy necessary for creating a sense of

safety within our interactions. Despite interruptions posing a threat to our research, our bodies and voices persevered.

Beyond the embodiment of crip time and improvisation, the process was further enriched by the intentional incorporation of reflection and pauses. In her examination of how feminist spaces emerge through collaborative research, Harding highlights the challenge women may face in embracing reflection and pauses (Harding 2020: 10). Striving to sincerely cultivate a reflective environment accommodating natural pauses, I purposefully allocated time within our sessions and encouraged the women to reflect not only during our meetings, but also in the interstitial periods between sessions. Pauses allowed for moments of silence and contemplation, reducing the pressure to respond immediately and enabling collaborators to feel heard and respected. Often moments of pause or reflection revealed facets that might have remained obscured without adequate time and space. This atmosphere of patience and attentiveness further encouraged not only the sharing, but also the co-witnessing, of personal and painful experiences in a secure and non-judgmental space, ultimately fostering a sense of mutual support and validation. Moreover, nurturing a culture of reflection and pause naturally alleviated the constraints of linear time and injected a breath of fresh air into conventional notions of productivity. This approach enabled the duets themselves to extend into deeper manifestations of crip time and crip space. The freedom of these interludes provided a fertile ground for informed and deliberate creativity. It was within this space, guided and inspired by our individual and collective truths, that the painscape practices continued to develop as outlined in the subsequent section.

Decidedly, the sustained perseverance throughout this process is likely a testament to the significant influence of engaging with the methodological perspectives and practices outlined previously. Across each duet series, the improvisational approach, grounded in adaptability, flexibility, and heightened awareness and powered by a mutual desire to have endo pain seen, felt, and heard in unprecedented ways, facilitated co-existence and co-creation. Unlike the inadequate approaches to pain research mentioned in Chapter 1, I welcomed collaborators into a shared experience of time and real/virtual space imbued with a certain readiness for both the familiar and unfamiliar, the known and unknown similar to an improvisational dance. Our interactions were devoid of specific structures, measurements, expectations, or predetermined content, allowing us to concentrate solely on the present moment and authenticity. Our relationships flourished organically, fostering emotional storytelling, dynamic empathic engagement, and creative exchanges. Through the practice of 'presence' and being immersed 'in the moment' within these intersubjective interactions, we wandered safely, vulnerably, and meaningfully without a map or destination - together. With pain and disruption as our common ground, an intimate bond and possibility for co-transformation emerged through our bodies. No matter how our exchanges unfolded or where our interactions led us, improvising together, we embraced the uncertainty of the journey and derived excitement, connection, and hope from uncharted terrain.

The Traces of Pain

The enmeshment of Phases I and II intertwined my pain with theirs. Though the modalities introduced in Chapter 3 remained the same at their core, the distinctions between self and ‘other’ dissolved as the voices of our bodies reverberated within the art-making process. Drawing parallels with others’ approaches to painscaping (Padfield 2019), it becomes evident that these exchanges not only influenced aesthetics, but also steered the art-making in unpredictable and often intangible ways. The following section attempts to elucidate some of the mystery and intangibility around this collaborative process by revealing pivotal interactions, repetitive motifs, compelling narrative details, and correlating artistic explorations. Additionally, in conjunction with this material, the six subsections integrate analysis and reflection of the aesthetic and conceptual themes drawn out in Chapter 3 — around embodied agency, time/crip identity, and representation/expression of invisibility (some of which have already been touched upon above). The insights highlighted in these subsections constitute enduring impressions that, akin to the invisible threads mentioned in the introduction, weave through the practice, leaving behind traces of pain in the final artworks.

Sharing these accounts — of both artistic practice and collaborator pain narratives — I prioritise lived experiences and lived practices as valid and critical research data. Furthermore, this purposeful inclusion of writing aims to illustrate this research’s commitment to amplifying hidden female experiences; distil convergences between self and others; and highlight the ongoing synergy between narrative and abstraction. In this section, it becomes clear how the research practice distinctly serves as a framework for sharing endo stories and experiences.

Jessie

Jessie, of mixed Chinese and Malaysian heritage, is a proficient movement artist and poet with an MFA in Choreography. Possessing an intimate understanding of the artistic process, she is well-acquainted with my creative endeavours and has been extensively involved in the performance of my works. Our longstanding collaboration initiated in Hong Kong, where we creatively engaged for numerous years and travelled together for performances across various Asian locations. In addition, she assumed a lead role in my immersive performance piece, *An Evening of Meat* (2018), with multiple presentations in London. Beyond our professional association, Jessie is a close friend and confidante. Our enduring companionship has afforded us the unfortunate experience of witnessing each other endure moments of extreme pain.

‘I’ve said that so many times in my life growing up, like, oh, I feel like I’m being stabbed. Like, do we know what feeling stabbed feels like? No, probably not. But that’s what it feels like. I know what I mean.’ (Jessie, November 17, 2021)

Given Jessie's London-based residence and my location in America, our collaborative interactions occurred virtually through Zoom. Due to her historical involvement in my creative process, the non-verbal exchanges and creative explorations transpired seamlessly. Our discussions drew upon distinct past pain experiences, such as Jessie's recollections of emergency surgery in Hong Kong and her struggles with pain during menstruation preceding the surgery. The depth of our shared experiences has fostered a unique and profound mutual empathy and understanding.

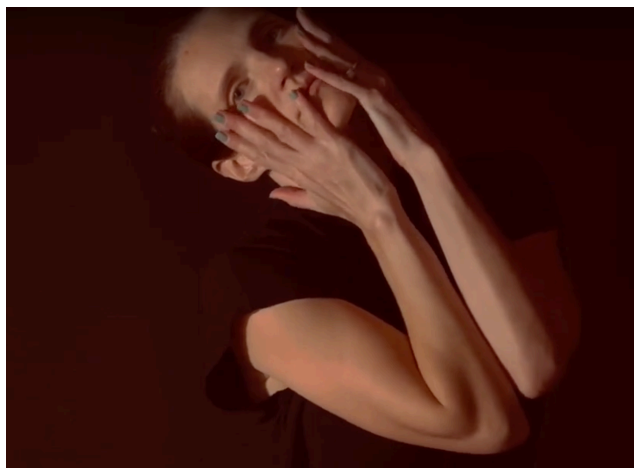


Figure 19. Phase II Practice: Screenshot from Filmed Movement Meditation (December 2021)

[Direct Link to Movement Meditation](#)

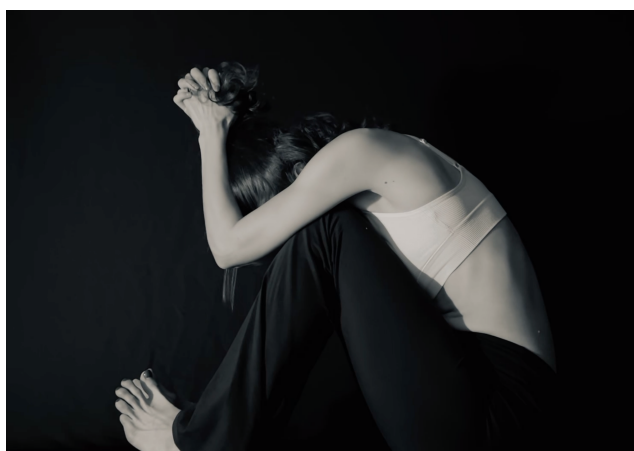


Figure 20. Phase II Practice: Screenshot from Filmed Movement Meditation (December 2021)

[Direct Link to Movement Meditation](#)

Recognizing the potential bias introduced by our close relationship, I deemed Jessie's participation essential after careful consideration. While I initially contemplated collaborating exclusively with individuals without a personal connection, I acknowledged that doing so might impede the richness of creative revelations in the research. Consequently, I approached each collaboration, whether with a familiar associate or a newcomer, as a distinctive opportunity for reflection, storytelling, exploration, and emotive expression. Despite our pre-existing familiarity, our collaboration commenced like others, verbally exchanging our stories to navigate new creative and personal terrain.

'Noticeably after that first surgery, of course that year, noticeably, my body felt free.' (Jessie, November 17, 2021)

'And it's funny when you ask me about pain? It's blurred out because I'm just so used to it now.' (Jessie, December 13, 2021)

'Although I feel the same way and relate wholeheartedly, I simply cannot believe a dancer like Jessie had felt un-free in her body for so much of her life. Connecting with her and others gives me empathy towards myself.' (Personal Duet Reflections, December 2021)

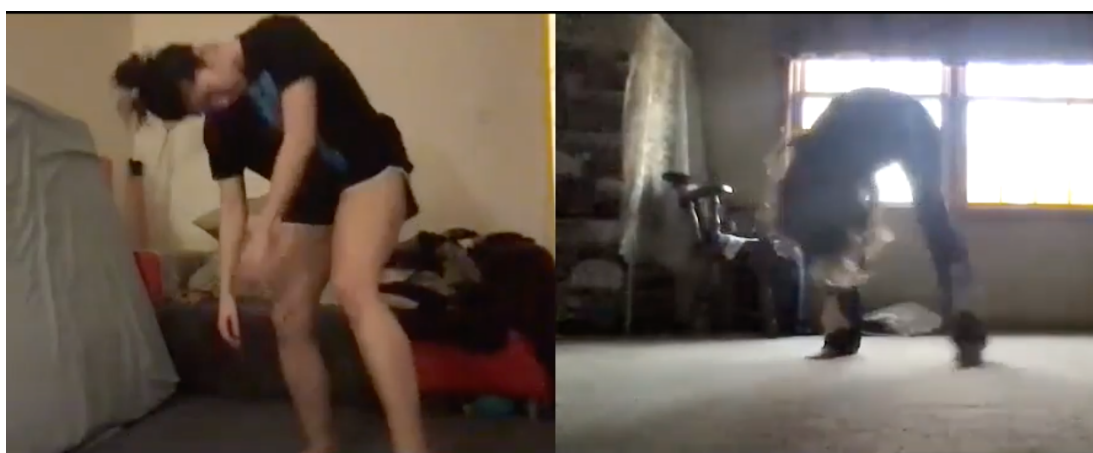


Figure 21. Phase II Practice: Screenshot from Zoom Session with Jessie (January 2022)

As our dialogues progressed Jessie expressed how much of her anxiety revolves around the resurgences of the debilitating pain associated with endometriosis, which could impose a state of stillness upon her body. With movement flow being a feature of internalised able-bodiedness originating in contemporary dance education, I empathised with her fear in the context of her profession as a dancer. Moreover, the prospect of undergoing surgery for the treatment of the disease and the ensuing immobilisation required for healing, contribute to her growing sense of terror. In her mind, the capacity for bodily mobility is integral to self-expression and personal freedom, and the fear of such movement restrictions constitutes a profound trauma. Endometriosis, while not life-threatening, poses a perpetual threat to her personal definitions of freedom and identity.

'The only thing I wrote...how I would describe the pain...I left it completely blank' (Jessie, November 17, 2021)

In addition to dialogues, Jessie and I approached the exploration of endometriosis pain and its consequences through non-verbal means and post-improvisation writing. Our dance improvisations

involved delving into movements that evoked a sense of freedom and conversely, movements that risked triggering pain. For instance, Jessie expressed in one improvisation her attempt to dance with abandon, embodying freedom from pain or surrendering to it despite the inherent prospect of pain. In contrast, I focused on movement ideas where specific body parts constrained the overall mobility of my body. Observing Jessie's body language, I translated elements into my own improvisational choices, incorporating floor-work to interpret her more vertical movements. Even in moments of fluid movement, both of us experienced distinct intervals of stillness, wherein our bodies seemed to succumb to fatigue. These moments potentially symbolised mental acceptance of pain or the chronic physical uncertainty, prompting reflective pauses. In our collaborative efforts, the exploration of stillness or slowness as alternative embodiments of freedom surfaced, thereby contributing to the manifestation of nether energies.



Figure 22. Phase II Collaborator Contribution: Screenshot from Jessie's Filmed Improvisation (January 2022)

[Link to Jessie Movement Meditation](#)



Figure 23. Phase II Practice: Screenshot from Wrapping/Movement Meditation (January 2022)

[Link to Movement Meditation \(in response to Jessie\)](#)

Over the course of my time with collaborator Jessie, we had a revelatory moment realising we had both had been creatively working with red string or red yarn in our quest to express something about or related to our identity as women with endometriosis:

'I was wondering if I can share something with you that I did nearly 3 years ago? At the time I only thought of it as my uterus and my association with it and pain, but not necessarily thinking about endometriosis. The project was about: how do I identify myself as being a woman....[Jessie proceeded to share white canvases with red string/yarn shaped into structures resembling or inspired by female anatomy or womanly shapes.]....I think there's something relatable to red yarn for a woman....Especially thinking about that tension of femininity of the material and the colour red.'
(Jessie, December 2021)

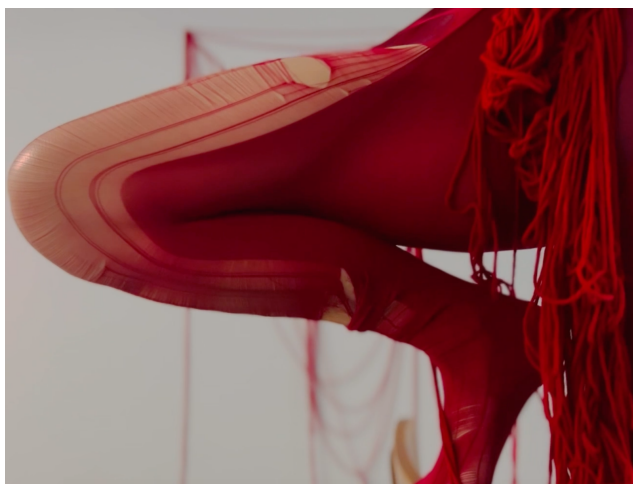


Figure 24. Phase II Practice: Screenshot from Performance Art /Movement Meditation Film (March 2022) [Link to Corresponding Performative Film](#)



Figure 25. Phase II Practice: Screenshot from Performance Art /Movement Meditation Film; Same video link as above. (March 2022)

Toby

Toby is a 67-year-old caucasian woman residing in South Carolina. She spent her formative years in the American South and dedicated more than two decades to educating children. Unlike Jessie and some of the other collaborators, she has no artistic background other than playing piano at church. Identifying herself as a person of faith, Toby sought solace in religion.

She joined as a collaborator during a chance encounter on a neighbourhood walk. She enquired about my doctoral research and unlike most people who ask me to elaborate on my research and are unfamiliar with the word endometriosis, her eyes lit up in deep recognition. She swiftly responded, ‘Well of course I know what that is. It’s the reason I couldn’t have children and it’s why I have suffered horrific pain’ (Personal Correspondence 2021). I invited her to be a collaborator at that very moment and she was more than eager to participate. Our four 90-minute sessions not only contributed to my artistic direction, but also kindled reflections on my own pain experiences. The material presented below reveals transformative moments from our dialogues and the artistic explorations directly inspired by Toby's lived experiences.

‘And I remember my mother would give me two tablespoons of bourbon to take the edge off. Yeah, or cough medicine.’ (Toby, February 8, 2022)

Her profound connection with the research’s emphasis on endometriosis was immediately evident. She endured undiagnosed pain throughout her life, only receiving validation of her suffering through infertility testing, which revealed the presence of the disease. Our face-to-face sessions held a distinct quality, marked by her remarkable willingness to candidly share experiences traditionally shrouded in secrecy due to the taboo surrounding female pain, menstruation, and infertility. Her openness was

noteworthy, especially considering her generation and the conservative cultural context of the American South. Given the secrecy surrounding her pain for decades, I felt a particular responsibility to honour her lived experiences. Her statement, *'the pain grew increasingly worse...and no one paid a lot of attention to it'* (Toby, February 2022), speaks to the urgency of acknowledging and caring for these long-muted narratives.



Figure 26. Phase II Practice: Screenshot from Movement Meditation (March 2022)

In addition to her verbal responses, Toby's body language conveyed a powerful narrative. Observing her in-the-flesh incision scars; witnessing tears welling in the corners of her eyes; providing her a moment to catch her breath during discussions of specific experiences; sharing a comforting hug after a particularly intense conversation; or sensing the shifts in her energy — these nuances of live interaction held an irreplaceable value. While virtual sessions with other collaborators also had a meaningful impact, the tangible, in-person engagements with Toby added an extra layer of depth and inspiration. (Note: in the feedback received from collaborators, the majority expressed a preference for Zoom sessions due to scheduling flexibility and adaptability.)

'Nobody ever told me that I may not have any children. Right. That was never, to my knowledge, mentioned. It does something to you that you never get over...Mother's Day. I don't go to church on Mother's Day. No, no. That's so painful. It's awful. It's just absolutely awful.'
(Toby, February 8, 2022)

In our initial session, I encouraged Toby to reflect on her earliest or most vivid experiences with endometriosis pain after sharing the background of my research. As she shifted to an attentive posture,

she vividly recounted the severe pain imprinted in her mind and body. Our discussion then turned to the unique pain cycle associated with endometriosis, distinguished by its acute and chronically cyclical nature linked to the menstrual cycle. As described in Chapter 2, unlike many diseases, the variable and relentless recurrence of pain poses a continuous threat making the navigation of time, space, and body challenging. Even after a successful surgery, the looming question is not whether pain will resurface, but when and in what form — be it infertility, scar tissue, painful sex, ovulation, cramps, migraines, or panic attacks. The anticipation of pain, the debilitating period, the recovery, and a brief respite from pain is the distinct four-part cycle Toby described. She emphasised endo's cyclical nature yet the pervasive anxiety-provoking unpredictability surrounding the flaring of symptoms outside of menstruation. Her articulations around pain's uncertainty and time not only resonate with my own experience, but also connect to the ideas in Chapter 2 surrounding non-normative temporalities, crip time, anticipatory scheduling, and crip futurity.

'Ok so it's like one week you're okay...Then the next week you know it's coming. The third week it comes. The fourth week you recover. And then guess what, it starts all over again. Ok. Not ok. Terrible. Then recovering to be whole again... for a short period of time' (Toby, February 15, 2022)

'To touch on this again, I've been consciously and subconsciously thinking about this concept of concealment so much lately. From a young age I have always felt embarrassed by how my period transformed me and my body. I'm sure much of it came from social and cultural rituals around menstruation. But deeper than that, I never felt good when I got my period. I never felt good leading up to my period. I also usually felt bad after my period. And so for me, because of my cycle, there was only approximately one golden week monthly where I felt like my true and joyful self. The pain made me feel like a monstrous and false version of me. I felt like my body was betraying me every time I saw blood start to flow and usually even before that moment too. I tried to feel normal and happy on the exterior by masking what was happening on the interior.' (Personal Reflective Writing, February 2021)

The thread of time as mentioned in Chapter 3 persisted even after diving into the discussion of the four-week cycle and the way endo tangibly propels us into a nuanced temporal existence. For instance, the concept of long-term time and timelessness in the context of chronic pain, particularly endometriosis, surfaced. I pointed out that in our sessions, neither of us was actively experiencing endometriosis, emphasising that we were conversing about memories. Related to my experiences in Phase I movement meditations, she agreed the term ‘memory’ seemed inadequate and hollow. Together we united in an awareness that due to its severity and chronicity in adulthood, endometriosis pain perpetually resides in our bodies and minds whether or not it is a current bodily sensation.



Figure 27. Phase II Practice: Screenshot from Movement Meditation Film (April 2022)

[Link to Movement Meditation/Film](#)

Certain time periods may offer symptom management or relief. Time might close some scars — both emotional and physical. However, between its incurability and its chronicity, the disease perpetuates as an integral part of one’s being. Even during moments of perceived control or remission, the pain lingers intimately, a constant haunting presence that threatens to disrupt any semblance of peace one might currently enjoy. Endo’s expansion of time, where its sufferer exists in an embodied and temporal limbo between past and/or present and/or future, was solidified in our collaborative time together. This experience of time aesthetically manifested as a kind of underlying hauntedness and inspired darker undertones in mood and atmosphere as well as non-linear storytelling.

‘It just...it did something that I think is undoable...to you psychologically. I really do. No matter how many years...you know?’ (Toby, March 18, 2022)

Moreover, it was during this initial discussion with Toby, concomitant with the Jessie duet series, that I began to discern and recognise our collective experiences as a manifestation of trauma (as touched upon in Chapter 3). Gradually, I apprehended the trauma associated with endometriosis, unfolding cyclically within the four-week period and accumulating across decades of these cycles. Analogous to any traumatic event, notwithstanding the absence of current physical pain, these memories persist, deeply ingrained in mind and body, readily accessible for expression. The lucidity of past pain, or

‘residue’ as described in Chapter 3, was accentuated when collaborators, irrespective of their present experience of pain during our interactions, articulated their pain as if presently experiencing their lived body experiences. In the exchange of narratives involving personal trauma, I came to realise the profound act of bearing witness to each other’s experiences. Thus, the emergence of the concept of trauma in the research was paralleled by the recognition of co-witnessing.

I inquired with Toby, as I did with all collaborators, regarding bodily postures she naturally adopted in response to pain or positions assumed in search of relief. She demonstrated, holding her head with both hands and illustrating a doubled-over stance. A particularly poignant revelation was her acknowledgment that, despite the ineffectiveness of screaming in relieving pain, it sometimes felt like the sole recourse. To avoid being overheard by others, she would wait until her husband was away, then stifle her screams with a wet washcloth (Toby, February 2022). This portrayal by such a petite and gracious woman, emblematic of Southern charm, exhibited vulnerability and rawness. The act of miming screams, despite their inability to alleviate pain, conveyed a profound sense of desperation. This evocative image of Toby, gesturing a silent scream, remains indelibly imprinted in my mind, persistently influencing and inspiring my creative endeavours (refer to Chapter 5).

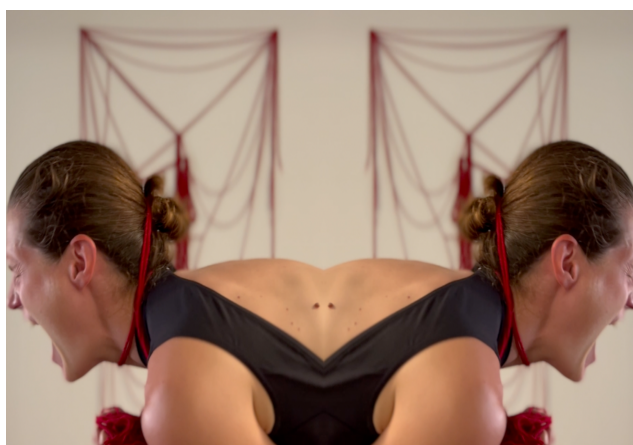


Figure 28. Phase II Practice: Screenshot from Performance Art/Movement Meditation Film (May 2022)
[Link to Performative Film](#)

On multiple occasions, I reviewed my artistic journey and creative inquiries with Toby, seeking her perceptions and insights as I endeavoured to express her/my/our pain. In an early session, after deactivating the audio recording, I presented some of the pre-collaborative paintings to Toby. Despite lacking a background in art, she displayed eagerness to examine them. Her responses included nods of approval, while certain paintings deemed aesthetically pleasing or beautiful elicited comments like ‘too mild’ or ‘too pretty’. Reflecting upon Toby’s observations, it became apparent that the Phase I paintings exhibited a certain degree of harmony or a semblance of being ‘put together’ despite the intention to convey the chaos and turmoil associated with endometriosis and internal bodily trauma. This interaction marked a turning point for the research, signalling a progressive shift towards a less comforting, cohesive or harmonious aesthetic. At this point, the painting and performance art

modalities began to more authentically embody endo's darkness and 'ugliness' in a more deliberate engagement with the abject, messy, and grotesque.

'We have a nice comforter and I'll take it off the bed and I'll lie on the floor. It's very cosy. There's something about the floor.' (Toby, March 18, 2022)

For instance in the painting practice, the initial inclination to exert control over the portrayal of pain gradually diminished, giving way to a reduced desire for an idealised or structured aesthetic. I yielded to 'the gap' where time and space exist in suspension, providing a momentary release from the constraints of judgement and perfectionism (as mentioned in Chapter 2 discourse from Nancy Stark Smith). The paintings underwent a transformation, moving away from a composed and restrained aesthetic toward a more unrestrained expression, best exemplified in the kinaesthetic painting practice detailed in Chapter 5. I introduced greater layering of paint and sand to create rough textures and diverse shades of colours, embraced formlessness, and allowed for random disruptions of shapes. I intentionally abandoned preconceived notions of formal structure. While instances of control sometimes resurfaced in post-performance moments, leading to intuitive modifications of colours or textures to align with the experiences of collaborators or myself, the overarching shift was towards a more liberated and spontaneous artistic expression which provided a deeper sense of agency and empowerment.

Additionally, the performative experimentations increased with a growing use of certain props, costumes, makeup, wigs, or masks. These additions further served to manipulate, disguise, or distort the narrative and expression of pain. For example, in its function as a binding agent, the yarn delicately stitched together a fractured yet resplendent body and woman. As the yarn was gently unwound, a sensation of invisible threads persistently tethering my body, past, present, and psyche permeated. The vanishing yarn evoked the proliferation of scar-inspired poetry, encouraging contemplation on the dichotomy between the visibility of physical scars and the invisibility of emotional or psychological wounds, and vice versa. Some of the resulting imagery is reminiscent of bondage as the yarn wraps the body like a dominatrix's rope might. It remains unclear what the body is experiencing and what the viewer is witnessing: pain or relief / control or freedom? Is the yarn wrapping to hide or control pain? Does the unravelling of yarn represent revealing pain or freeing the individual from its grasp? Frequently, within the in-between moments where the yarn was both tightening and loosening around my body, I seem to straddle performance and reality; human and creature. Additionally, the increased use of tangled yarn both as backdrop and prop added another layer of chaos to the imagery; disturbing any aesthetics of organisation/order being portrayed.

'Abstract art does nothing for me, but some of these are like... okay... I get it....Oh Kate. Oh my. This...Oh this speaks volumes to me right here. Oh Wow...' (Toby, March 30, 2022)

Similarly, in the edited film content, I enunciated gender identity by incorporating stereotypical female elements like high heels, pretty masks, dresses, skirts, or the use of tight fitting leotards or pantyhose. The integration of these materials served dual purposes: the creation of a hyper feminine or sometimes sexualised persona, deepening endo's association with gender, and also, significantly, the sculpting of traditional 'female' aesthetics of beauty, symmetry, or harmony. Both of these intentional constructions were simultaneously dismantled in a manner similar to the painting practice: upon close inspection, harmony or a sense of wholeness was severed or skewed.

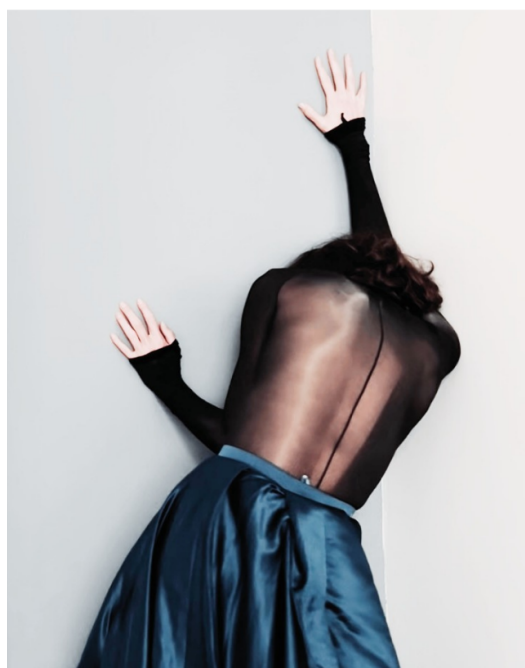


Figure 29. Phase II Practice: Screenshot from Movement Meditation Film (April 2022)

For example, the tights are worn, torn, and ripped. The body is not necessarily elevated by the high heels; instead it teeters and slumps. The flowers and colours on the masks are generally pleasant, but the absence of facial expression caused by them can be perceived as unnerving. At other times, the masking provides a sense of anonymity which either serves to hide my brokenness from the camera/viewer or etch the notion of 'every woman' into the imagery. The skirt is voluminous and elegant, but conceals the lower body's struggles and seems to overpower the performer's agency. In some moments the portrayal of anxiety and grief is magnified because of the costuming/masking, while in other instances, removing the costumes/masks/wigs expresses liberation and reflection. This imagery seems to encapsulate the woman and the disease simultaneously, revealing their coexistence.

Increasingly weaving less easily classifiable aspects of performance and visual art expanded the possibilities of representing and bridging the gap between visibility and invisibility, inclusivity and oppression. Other questions around expression and representation emerged: Do particular pain experiences evoke distinct colour hues? Might gendered pain be saturated with its own distinctive colour palette? How might we describe the atmospheric essence of endo pain? What sensations and characteristics define the interior landscape of endo, and how are these inner realms externalised?

What do the monsters that dwell within our bodies look like? What is the relationship between beauty and pain? These inquiries compelled me to consider the boundaries of representation and challenge societal norms, inviting deeper reflection on the complex interplay between our bodies, identities, and experiences in Phase II. Through collaboration with other women, the exploration of pain becomes more expansive and inclusive, offering diverse perspectives and narratives that enrich the conversation surrounding in/visibility and representation.

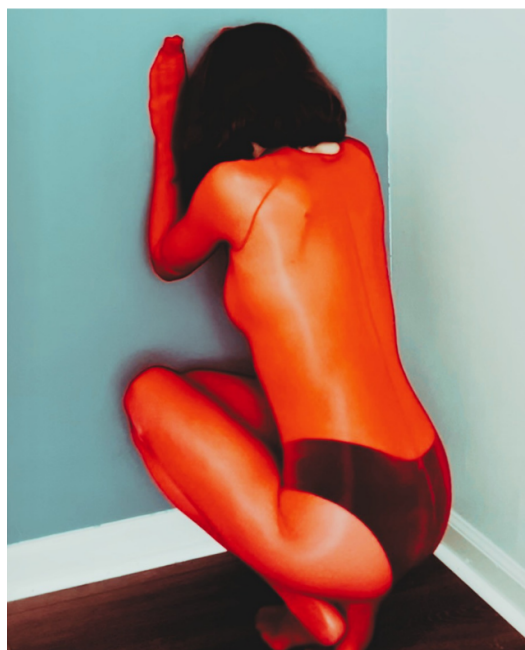


Figure 30. Phase II Practice: Screenshot from Movement Meditation Film (April 2022)

In relation to these developments, although colour ultimately is not a major conceptual facet of netherness, it inherently contributed to the aesthetic expression and representation of pain and was an unavoidable element of these exchanges worth noting. Moreover, specific colour combinations might create atmospheres reflective of the hauntedness of pain memories or the violence of pain's sensations. Notably, the salience of certain colours in the realm of painscapes is not completely fortuitous, but likely influenced by culturally ascribed perceptions and experiences.

For instance, the original colour palette that emerged in the Phase I & II body of work included red, black, grey, purple, and pink. These colours have distinct cultural associations to menstruation, pain and Western codes of quintessential femininity. These colours are not frequently part of my artistic process outside of this research and yet, in the space of endo experiences, these colours felt dominant and instinctively fundamental. In Phase III, the colour palette evolved to intuitively capture the 'effervescence' (Albright 2018: 59) of each collaborator and to better reflect the dissident tone of netherness.

'You used your red. What colour are you going to use to put yourself back together?...' (Toby, March 30, 2022)

Chelsea

Chelsea is a Caucasian woman in her early to mid-thirties residing in New York. The introduction to Chelsea was mediated by a mutual artist acquaintance, who conveyed Chelsea's recent endometriosis diagnosis and desire for connection with other endo sufferers. Like Jessie and I, she holds a professional background in both dance and visual art. This shared background lends a unique facet to our collaborative sessions, facilitating dialogue through verbal communication, movement, and painting.

'I don't know. I guess a normal amount of pain. Sometimes I can't ride my bike because of pain. Or a few times I have had to sit down on the corner of a city block otherwise I might pass out. A few times I have blacked out. Sex is painful. To the point where we just...it's kind of not a thing now....But...isn't that all normal pain?...'
(Chelsea, January 25, 2022)

Our introductory conversation, preceding the research collaboration, unfolded unexpectedly, revealing the diverse impact of endometriosis on individual journeys. Chelsea underwent surgery initially presumed to address a hernia, but awoke with an endo diagnosis. Sensing a tumour in her right hip during yoga, she experienced escalating discomfort without reaching excruciating pain. An ultrasound disclosed a mass affixed to her hip tendon, misdiagnosed as a hernia by her previously trusted gynaecologist. Despite the surgeon's scepticism about it being a hernia, surgical removal was recommended. Subsequent biopsy results identified the mass as an endometrioma cyst. The atypical surgery left a sizeable incision, extending the healing process.

'What hurts? My actual vagina, my lower back, my ass, like everything' (Chelsea, January 25, 2022)

Amidst recovery and grappling with her new diagnosis, Chelsea literally wept to me and expressed a profound sense of feeling 'out of her body' characterising her body as foreign and unfamiliar. The intrusion of an incurable and unpredictable disease in her pelvis and reproductive region represented a significant assault on her identity as a woman. In alignment with Jessie, who articulated a sense of an 'unfree' vs. 'free' body based on endometriosis infiltration, Chelsea contended with a disrupted connection to her body and, disconcertingly, her sense of self. While other collaborators communicated life disruptions and the consequent feeling of dislocated self due to endometriosis, the poignant sensation of feeling cyclically disconnected or estranged from one's body resonated particularly strongly with the dancers involved in this research (Chelsea, Jessie and me).

When asked what her body does when experiencing pain: *'Fuck, I don't do anything. I*

like literally say hello pain, welcome, take a fucking seat. I feel, like, completely powerless.'
(Chelsea, February 2022)



Figure 31. Phase II Practice: Screenshot from Choreography Documentation (September 2022)
[*Choreographic Exploration Documentation*](#)

In the beginning of our duet series, Chelsea downplayed her menstrual pain while acknowledging her high pain threshold and the capacity, as a dancer, to persevere through painful limits. Despite her belief that she endured minimal disruption from physical pain, in ongoing dialogues, as she reflected on past experiences, it became clear that Chelsea's life was profoundly impacted by the endometriosis. For instance, besides severe pain memories being unpacked, she discussed a prior visit to a fertility doctor revealing her inability to conceive naturally which instigated considerations of freezing eggs for future IVF. Her intensive exploration of literature on endometriosis and its associated fertility challenges suggest the substantial impact the diagnosis had on her life. I endeavoured to provide empathy and resources in response to the turmoil she was navigating.

'I actually thought about the last time we spoke because it was the first time someone wasn't minimising what I had experienced ...There's no way to say "I suffer from a chronic illness that affects me daily but I'm not going to die"...'
(Chelsea, February 2022)

As our exchanges progressed, Chelsea consistently identified the lack of control and agency associated with disabilities and invisible, incurable diseases as a central concern; reflecting similar feelings expressed by other collaborators and myself. The inherent unpredictability and uncertainty compel us to relinquish control and acknowledge the limitations in orchestrating our well-being. While proactive measures and advocacy for optimal care are within our purview, absolute control

over our bodies remains elusive — this can feel powerless — maybe particularly for trained dancers. Navigating this uncertainty amplifies our somatic awareness, with every physical sensation prompting contemplation about what might transpire next. We exist in a perpetual state of anticipation, serving as both participants and spectators to our own pain. For artists, engaging with this notion involves the active expression of our pain. An illustrative example is Chelsea and my collaborative effort to articulate the experience of migraines. In this particular task, we found connection, strength, and even levity by transforming our pain into art. Despite the lack of control, the absurdity and the ugliness of our migraine pain, we held onto hope for positive change not only within our bodies, but within the artworks themselves. Sharing our painscapes and striving to connect through our suffering proved to be the most poignant aspect of our artistic expression, leading to transformation, transcendence, connection, empowerment, and coping.

'How do I put this [holding her left eye and head which is where she experiences migraines] on a canvas?...It [referring to the painting] will...it will turn into something (laughter). It will... But right now, I'm staring at this ugly piece of shit that I wasted time on...(laughter)...that doesn't express how I'm feeling [referring to the migraine pain] at all (laughter)...' (Above: Chelsea, March 2022; Below Figure 32 is Chelsea's Painting & my painting response Figure 33, March 2022)



Figure 32. Phase II Collaborator Contribution: Photograph of Painting (March 2022)



Figure 33. Phase II Practice: Photograph of Painting (April 2022)

In our duet series, Chelsea’s profound shifts in perception and newfound insights into her life were palpable. Chelsea’s story illuminated the intricate and multifaceted nature of the ‘pains’ associated with endometriosis. While physical pain frequently serves as the primary catalyst, it unfolds into various other dimensions of distress such as fear, anxiety, anger, and sadness. Even in the absence of acute physical pain, the disease’s impact on anatomical facets culturally linked to womanhood and female identity generates profound emotional distress.

Furthermore, a significant aspect emerged in our dialogues with Chelsea — the concept of intergenerational pain. This became particularly intriguing as I reflected on my own experiences. The shared history of endometriosis among my mother and grandmothers virtually predetermined my own encounter with the disease, and, in a poignant realisation, I recognised that I bear not only my pain but also that of the women preceding me. This revelation prompted a deeper contemplation on the scars passed down through generations, leading to the intention of loosely incorporating my mother’s endometriosis experience into my painscape which is discussed in Chapter 5.

‘Ummm. Epic. I realllllly resonated with the “stuck in the pain web” film ...the music and the vivid and stark images of the blue and black on the white background. Very powerful...’Sewn back together and Past Lives Haunt us feel like a trilogy of sorts with that one. Wondering if “womb resilience” is part of that?...slightly scary...’ (Chelsea text message in response to below film, March 2022)



Figure 34. Phase II Practice: Screenshot from Performative Movement Meditation Film (April 2022) [Link to Performative Film](#)

Mei

Mei, a 33-year-old resident of Hong Kong and an acquaintance through mutual friends, encountered a transformative journey with endometriosis. Initially, she had been on birth control for most of her twenties without significant pain issues. The decision to discontinue birth control at the age of 29, as she and her then-husband sought to conceive, marked a pivotal juncture. Post-withdrawal, Mei experienced three consecutive periods of excruciating pain, characterised by stabbing sensations in the front lower pelvis. The intensity of the cramps rendered her immobile, with the aftermath leaving her unable to stand upright for three days due to the extreme contraction of her uterus and surrounding muscles. Mei attributes the onset of these health challenges to the removal of her intrauterine device (IUD), deeming it the moment when everything ‘went WRONG’ (Mei, March 2022). This narrative of bodily deviations and inherent ‘wrongness’ becomes a compelling theme for creative exploration in *Nether Space(s)* and netherness in general (see Chapter 5 and Chapter 6).

Despite seeking medical attention, her pain persisted, and a subsequent examination revealed two cysts on her ovaries necessitating surgery. The recovery from the surgery, lasting eight to twelve weeks, was accompanied by discomfort and abdominal bloating. Mei’s struggle to conceive persisted, leading to attempts such as intrauterine insemination (IUI). The emotional toll and challenges, however, strained her marriage to the point of dissolution. This poignant narrative exemplifies the profound impact of endometriosis, encompassing physical pain, surgical interventions, and the emotional complexities surrounding fertility and relationships. The resounding emotions shared in our exchanges were around shame and anger — both of which I repeatedly explored creatively as demonstrated below and in Chapter 5.



Figure 35. Phase II Practice: Photographs of Paintings (March 2022)



Figure 36. Phase II Practice: Photographs of Paintings (March 2022)

Beyond our interactions, Mei explored her pain experiences through words and musical choices shared with me. She selected dark music, reflective of her pain and severe experiences, serving as a poignant source of inspiration for my movement meditations, poetry, and painting rituals. Additionally, the melding of her experiences, expressed through her verbal reflections and music, adds depth to the artistic dialogue surrounding the complexities of living with endometriosis.

Mei describes music she sent to me: *'The white noise in the background against the deep strokes*

of the bow vibrating... “vibration”– That’s what triggers my memory of my pain. The strokes of the bow signifying the stabbing pain in my uterus - increasing then decreasing over and over again. The vibrations - that white noise you have in your head when you are in the most excruciating pain - like nothing around you matters. You just want to focus on the pain and your body’ (Mei, May 2022)

Significantly, Mei’s resonant expression of feeling like a ‘broken woman’ summarises the profound impact endo had on her self-perception; inviting further reflection around the notion of ‘split self’ and its implications in the creative process. The dichotomy of being ‘broken’ and aspiring to be ‘whole’ prompts a deeper inquiry into the societal attachment of identity to the female reproductive system. Questions emerge regarding the significance of womanhood tied to the integrity of one’s womb. Likewise, the persistent frustration and the looming uncertainty surrounding the disease’s trajectory become focal points for artistic exploration.

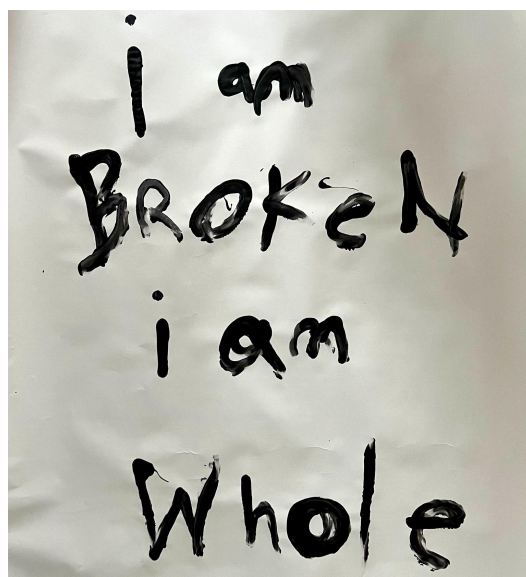


Figure 37. Phase II Practice: Photograph of Painting (May 2022)

Mei’s proactive decision to undergo an egg retrieval for potential future IVF procedures emerges as a source of empowerment, a deliberate action against the potential challenges of conceiving with endometriosis. Amidst her complex relationship with the disease, the monitoring of a growing cyst introduces a layer of ambiguity, as her current lack of discomfort contrasts with the looming presence of a medical concern. This period of non-pain becomes a focal point of her efforts to maximise its respite. Until, she was interrupted.

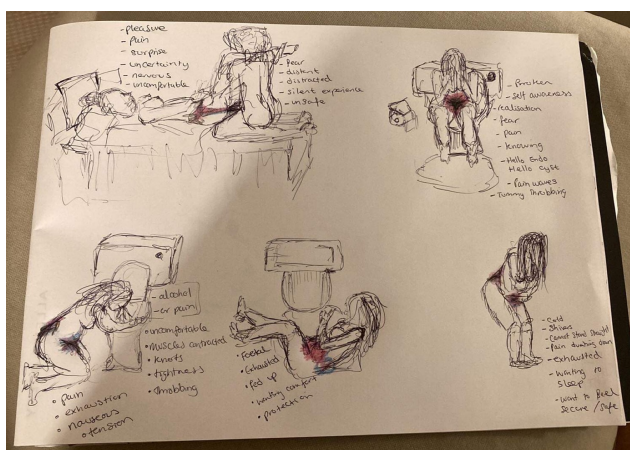


Figure 38. Phase II Collaborator Contribution: Sketch (August 2022)

'Hey Kate, so I wanted to message you as I think I may have experienced my first endo episode after a very long time. I hooked up with a guy I knew last night. As sex was causing stabbing pain we stopped. Then the cramps came, pain in waves but they weren't disappearing. So I went to the bathroom. I sat on the toilet, leaned forward and put my head in my hands. I didn't know what to do. Sitting up made me feel uncomfortable and didn't feel right so I leaned forward. Then I felt the urge to vomit. I did... The cramps still came and went. After vomiting it got more intense I guess from my tummy muscles contracting. So I sat on the floor crouched over my belly with my knees up. I tried rubbing my tummy, maybe I need to move my bowels. I sat in the bathroom again but not much came out. Then the pain increased... I was also exhausted (it was 2am/3am). All I wanted to do was lie on the toilet floor in a foetal position. So I did. The pain was easing. The whole time I was going in circles in my head... oh no it's the endo it's back.. oh no, not now.. why tonight... what about my next egg freezing treatment? Oh no I have to go to the doctor. Oh no my gut feeling is telling me it's my endo ... oh no I have to have surgery again.. the stress of my pain and reality of what I am going to have to do set in... I also kept checking for vaginal bleeding, a common sign for me. The pain was getting better in the

foetus position so I thought ok now I can go to bed. When I left the bathroom I felt vulnerable and cold. I couldn't stand up straight. I put a dressing gown on and got into bed and lay on my left side with my knees quite high... I know this pain... I wish I didn't but I do...hello darkness my old friend. Can we reschedule our zoom for today?...' (Personal Correspondence with Collaborator Mei in the middle of the night, July 2022; Above: Mei's drawing August 2022).

Following the sudden and unexpected onset of pain, I inquired about Mei's perception of 'healing' to which she responded negatively. She articulated that her body bears the sensation of 'a ticking time bomb' (Mei, August 2022). We concurred on the notion that the healing process remains perpetual and never truly concludes due to the relentless nature of endometriosis. Perhaps 'coping' is a more accurate term and strategy — an honest acknowledgment of the ongoing challenges posed by a disease of such enduring and uncertain nature as endo.



Figure 39. Phase II Practice: Screenshot from Performance Art/Movement Meditation Documentation (August 2022)
[Link to Movement Meditation/Film](#)

Mei's poetic use of language or imagery to describe emotions or existential states connected to her pain, embodiments of pain or comfort, and her corresponding selection of music, significantly influenced the improvisations. This impact provoked explorations of dualities such as 'right and wrong' or 'broken and whole' particularly within the context of coping. The explorations that were shaped by my interactions with Mei, both physically and emotionally, brought me into new environments — places where I sought wholeness, harmony, and hope. These were spaces where my broken self and whole self felt less like strangers, exemplified in nature.



Figure 40. Phase II Practice: Screenshot from Performance Art/Movement Meditation Documentation (August 2022)

Introducing more moments of rest and recovery, embodying alternative energies and temporalities, while also honouring pain's inexpressibility and unknowability, appeared to allow a more accessible and concrete version of what Kafer refers to as an anti-ableist 'elsewhere' and 'otherwise' to emerge. At this juncture in the research, an impetus of dynamically constructing painscapes as portals and manifestations of 'elsewhere' instead of simply theorising about such became more intertwined with the unfurling netherness praxis. Additionally, the recurrent exploration and experimentation with embodied dualities and juxtapositions throughout these duets led to a robust contemplation of the endo identity and body as existing as a kind of liminal 'elsewhere' in and of itself. Concepts of liminality and a more intentional creative exploration of liminal aesthetics continued to unfurl.

'Yeah, so I really liked how bizarre it [performance art film link below] was. And it's funny when I watched the film, it's almost like, at least right now, it's like, I feel like the character in this film is actually like the endometriosis itself. I can't see your face. I can't see your hair, so you're not human in a way. Yeah. But you have that human figure as well. So it's, yeah. It's almost like, you know. You know, it's like putting on a mask, you become something else, right? Yeah. It's kind of like this little monster. Actually, big monster.' (Mei, May 2022)

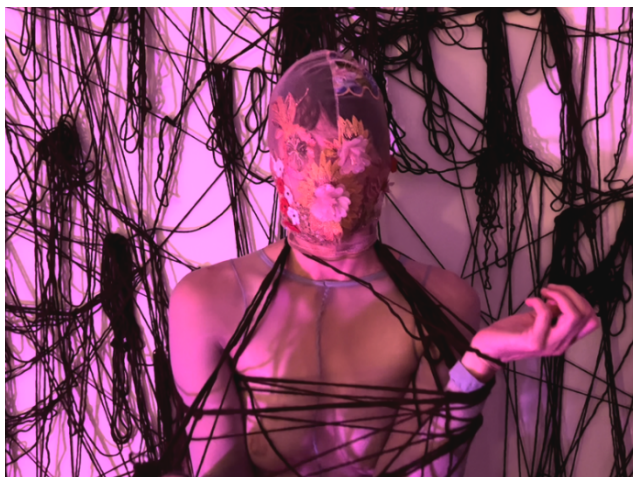


Figure 41. Phase II Practice: Screenshot from Performative/ Movement Meditation Film (May 2022)
[Link to Performative Film](#)



Figure 42. Phase II Practice: Screenshot from Performative/ Movement Meditation Film (July 2022)
[Link to Movement/Performance Meditation](#)

Danielle

Danielle is a 36-year-old Sri Lankan woman based in Singapore. We were first introduced several years ago through a mutual friend, and our long distance friendship blossomed particularly as we underwent IVF treatments concurrently. At the time of our interactions, she had recently been diagnosed with endometriosis as a result of infertility diagnostic testing, not as a consequence of pain per se. Similar to Chelsea's experience, Danielle's awareness and insight into the perpetual normalisation of severe pain episodes was post-diagnosis. With the clarity of hindsight, she realised the pain she was suffering throughout her life at various times was not normal though culturally it was not an option to openly discuss such 'inappropriate' experiences (Danielle, May 2022).

'I feel like unless you've had these kinds of experiences, it's a hard thing to wrap your head around, actually.' (Danielle, May 2022)

'Honestly, I feel like my endometriosis hit me like a truck. Because it just happened, I'd say it was just overnight. I was already like a day or two into my period when I got the pain and I literally thought I was going to die.' (Danielle, May 2022)

'I just took a bunch of Tylenol. I couldn't fall asleep. It was so bad. I just felt like stabbing and like, you know, the usual, like, like I'd swallowed nails or something. It was just so bad. The next day, I was exhausted' (Danielle, May 2022)



Figure 43. Phase II Practice: Photograph of Painting (March 2022)

Danielle vividly conveyed her symptoms in our sessions, leaving a lasting impression with such metaphorical descriptions. Through our dialogue she relayed the moments both before and after surgery wherein she was forced to adopt the (common to endo) posture of walking bent over, embodying the endurance and strength necessitated while suffering from endometriosis related pain. The emotional toll of multiple IVF failures led to her profound sense of ‘numbness’, inspiring consideration around how a disease or disability can induce feelings of failure and angst, even when it is not the individual’s fault. Our dialogues echoed Mei’s verbalised emotions of shame and anger.

'I thought I was taking care of my body, I thought that I was like, you know, this fertile

goddess and I should get pregnant. And when it didn't happen and I got the endometriosis diagnosis, I was just so hard on myself. I just punished myself for so long... You put the blame on yourself and then there's anger towards the body... For me it was so sad because I got the diagnosis after I had the miscarriage' (Danielle, May 2022)



Figure 44. Phase II Practice: Photograph of Painting (May 2022)

Referencing the DNC procedure for miscarriage: *'...so I went in, did it, I came back and I lay in bed for like, I think close to two weeks. I would just go into the guest room, close the curtains, lie in bed, you know, go back and forth from room to room. John would follow me and open the curtains, I would get annoyed, go to the other room, close the curtains' (Danielle, May 2022)*

Despite the negative connotations of such expressions and the obvious suffering she had endured, she maintained an upbeat vocal delivery at the time of our exchanges. Often through her humour, calm demeanour, and mutual moments of levity, the absurdity of these intense and inexpressible experiences was highlighted. This juxtaposition seemed to solidify how unravelling shared experiences of pain might also serve as opportunities for connection and transformation. Specifically, because of our coinciding IVF histories, much of our interactions originated in unpacking these collective experiences. Sadly, her six failed transfers generated a distinctly immense pain.



Figure 45. Phase II Practice: Photograph of Painting (May 2022)



Figure 46. Phase II Practice: Screenshot from Performance Art/Movement Meditation Documentation (June 2022)

'The IVF was almost like I was stuck in a kind of quicksand and it was making us and time stand still. Because it was just, okay, we can get on with our lives after this is over, you know, this "thing" that's just so gruelling and so taxing...I was just like a zombie basically...Everything was just numbness...' (Danielle, May 2022)

A unique aspect explored with Danielle was a body's repeated exposure to the medical context and what emotions and experiences surface as a result. She articulated the overwhelming fear and exhaustion experienced in hospitals in juxtaposition with the solace and restfulness she experienced

under anaesthesia which she referred to as ‘an escape from the doctors and the hospital and the disease’ (Danielle, May 2022). These complicated feelings resonated with my own experiences, provoking reflection on the uneasy, uncertain, and surreal feelings associated with medical environments. In the final choreography of *Nether Space(s)*, I aimed to explore this strange and unsettling state, acknowledging the familiarity and daunting fear that medical treatments and contexts might hold for individuals with chronic and remitting diseases.



Figure 47. Phase II Practice: Screenshots from Performance Art/Movement Meditation Film (July 2022) [Link to Performative Film](#)



Figure 48. Phase II Practice: Screenshots from Performance Art/Movement Meditation Film Same link as above. (July 2022)

'Waiting, there's so much waiting. And you can't really relax... No, you're just on the edge of your seat the whole fucking time you're waiting... unless you're under.' (Danielle, June 2022)

Danielle's narrative emphasised the longer journey endometriosis patients face in coping with such intense emotions and experiences. The concept of resilience in the more conventional terms as 'warrior' or 'endo warrior' permeated many of the collaborator exchanges, though I felt this profoundly in my dialogues with Danielle and it prompted me to approach some of the movement expressions and performative films with a sense of attack, vigour, and 'warrior' mentality contrasting some of the more crippled embodiments of resilience as discussed in Chapter 3.

'I also wanted to tell you that for me, the pain after the surgery was super painful... when I would get up to go to the bathroom in the morning or to pee or to like poop like the pain was literally as if someone punched me in the face. Like I would have to hold the sides of the walls and I just closed my eyes and you know like when you see stars?' (Danielle, June 2022)

'I mean my worst pain to this day was right after my first laparoscopy... I was walking bent over. And I really wanted to still have my family over and be social, but they were just like, we think you should lie down because you don't usually walk like this. And I'm just like, no, I'm fine... Just walking completely bent over. And they're like, no, no, no, you sit down. And I was like, no, no, no, we're having a party right now...it all just numbed me.' (Danielle, June 2022)

Fortunately, in our final exchange, relief, healing and acceptance emanated from Danielle. After her marriage dissolved as a direct result from infertility battles (similar to Mei), she committed to self-care practices through traditional therapy, animal therapy, and artistic expression. I viscerally witnessed how taking a break from IVF encouraged a deeper sense of clarity and reconnection to self and joy. Over time and with conscious intention, she shifted from feeling burdened by her body to nourishing her body and mind on multiple dimensions (food, nature, exercise) in an effort to co-exist with the disease and be prepared for any future battles. The overall sense of failure and numbness she described transformed into a resolve to rediscover joy. This warrior genuinely demonstrated the power and agency that pause, stillness, and self-care invites into the endo experience. Amidst the darkness, Danielle was a beacon of beautiful, absurdly playful, hopeful light contributing to the overall felt sense of illumination in Phase II.



Figure 49. Phase II Practice: Screenshot from Performance Art/Movement Meditation Documentation (August 2022)

[*Link to Warrior Movement Meditation*](#)

The Developing Reflections

As the preceding subsections illustrate, the co-creative explorations with these five women advanced understanding of key conceptual and aesthetic themes — around embodied agency, time, and in/visibility — that first emerged in Chapter 3 correlating to the explorations around my own experiences. Significantly, this phase, distinguished by collaborative interactions, also brought the concept of witnessing forward, as well as, relatedly, the transformative power of validation and the significant impact of enhanced visibility. At times these themes were subconsciously navigated; only fully recognised upon reflection. At other times, they were purposefully drawn upon, especially in the context of examining the enduring impacts of pain—its memories and scars—and the notion of a split self. In any case, the developing reflections that occurred over the course of this phase drove Phase III (the focus of the next chapter) and eventually invited contemplation around this project’s relationship to activism and advocacy work (expanded upon in the Conclusion).

Witnessing, Visibility, & Validation

My role as artist and facilitator in Phase II propelled me into becoming a witness to the collaborators’ pain. Likewise, my increasing film-work and performativity invited the collaborators to become witnesses to my pain. As such, over the course of this research stage, I began to theoretically engage in more nuanced considerations regarding the ethical and empathetic witnessing of pain and trauma. Particularly, I explored the role of witness within feminist perspectives, disability studies, narrative medicine, and trauma/pain research. This investigation properly contextualises its inclusion in an endo-painscape practice and demonstrates its relevance, across diverse disciplinary perspectives, in fostering connection, visibility and solidarity.

For instance, previously mentioned scholars Sara Ahmed and Rosemarie Garland-Thomson both offer valuable insights into the transformative power of witnessing through feminist and feminist disability lenses. Garland-Thomson's work in feminist disability studies sheds light on the role of witnessing in understanding and valuing disability experiences. She examines how representations of disability in literature and culture can both elicit empathy and challenge ableist assumptions (Garland-Thomson 1997). Similarly, Ahmed emphasises the importance of empathy as a tool for building connections and solidarity across differences. Ahmed's work accentuates the significance of empathy in challenging dominant narratives and amplifying marginalised voices, making it an essential component of a feminist praxis (2017).

Additionally, in the context of narrative medicine and trauma/pain, witnessing plays a crucial role in validating and honouring patients' stories and experiences (Charon 2006). Rita Charon's narrative medicine framework emphasises the importance of bearing witness to patients' narratives, recognising the power of attentive listening and compassionate interactions in healthcare settings. Likewise, in the realm of trauma/pain, Judith Herman's seminal work on trauma and recovery highlights the importance of bearing witness to survivors' experiences, acknowledging and affirming their pain and trauma through empathetic engagement (Herman 1992).

Lastly, within the domain of dance and performance art, the notion of witnessing takes on a profound significance. Scholars like Jill Dolan have highlighted the transformative potential of performance to bear witness to marginalised experiences, including those of trauma and suffering (Dolan 2005). Dolan emphasises the role of performance as a site for empathy, connection, and social change, underscoring its importance in creating spaces for marginalised voices to be heard and supported. Likewise, returning to Albright's work around surviving disorientation, she discusses the role of witnessing in *Authentic Movement (AM)* (2018: 194) where the reciprocity of seeing and being seen is a critical aspect of the practice; the foundation for 'mutual vulnerability' and 'care-taking'. The 'seeing and being' or 'hearing and being heard' that occurred in these exchanges certainly constituted the ground similarly: the collaborators' presence mattered as much as my presence mattered in evoking the power of testimony to claim agency in our frequently dismissed bodies/identities. These perspectives underline how both artists and audiences contribute to building inclusivity and fostering what has been termed as 'radical empathy' through shared witnessing experiences (Jamison 2014: 12).

I harnessed the idea that not only could my collaborators actively co-create meaning in this research, but the audience could as well. I deepened my established interest in blurring boundaries and dismantling traditional hierarchies between performer and audience by recognising them in the subsequent phase as ethical witnesses invited to see, hear, and feel expressions and embodiments of endometriosis. Such embodied resonance and participation can help us truly see, hear, feel, and empathise with an individual's 'effervescence' which in this research might include their pain (Albright 2018: 199). By embracing these experiences, despite the vulnerability they entail, we render the boundaries of ourselves more permeable. This permeability allows us to invite and engage with

another's disruption or disorientation, revel in their proximity, and bear witness to their experiences as well as our own.

The idea of witnessing or an intentional permeability between self and other is also realised in this thesis beyond its eventual incorporation in the final artworks. Indeed my witnessing and retelling of the collaborators' pain narratives, along with their direct quotations, within academic discourse demonstrates a wider scope of witnessing that speaks to the research's implicit potential for activism and advocacy.

The notion of witnessing along with its embodied acts within the collaborative art-making practice play a pivotal role in enhancing visibility/palpability and fostering validation for myself and potentially other endo sufferers. In verbal exchanges, the process of empathetically witnessing each other's personal narratives demanded a profound level of engagement, characterised by attunement, active listening and a compassionate presence that acknowledged and validated lived experiences (Frank 1995; LaCapra 2001). Additionally, co-witnessing the creative practices and outcomes created more experiential opportunities for endo pain to be recognised and affirmed, as the invisible and less definable suffering associated with endometriosis was invited into the light.

Eventually, our personal stories were shared through public-facing art and in this exchange, the community became an extended witness to collective pain. This broader witnessing transformed private suffering into a shared experience, thereby amplifying the visibility of endometriosis and challenging the stigma and silence that often surrounds it (Cvetkovich 2012). The communal act of bearing witness not only enhanced the legitimacy of these experiences (Kaplan 2005), but also forged a sense of solidarity and collective validation among collaborators. In the audience's engagement with the artistic expressions embedded with collaborators' narratives, they in turn acknowledge the reality of endometriosis, validating the sufferers' experiences on a societal level.

This increased visibility through public art serves as a powerful tool for advocacy, potentially influencing public perception, medical research, and policy (Butler 2009; Sontag 2003), ultimately leading to a greater validation of (endometriosis) sufferers' experiences and needs. Increasingly in the research, through collaboration and witnessing, the areas of visibility, representation, expression, and identity become inextricably linked. As such, the role of witnessing and collaboration in paving pathways for representation, validation and embodied agency will be expanded upon in Chapter 5 while a discussion encompassing the role of visibility and validation will be offered in the concluding chapter in relation to implications, applications, and trajectories for netherness as well as endo painscapes.

Conclusion: Unfolding towards Netherness in Phase III

'I changed orientation, and this shifted my approach to my art too. Part of this change in orientation was to move away from single-voiced poetry to a more open field' (Kuppers 2014: 333)



Figure 50. Phase II Practice: Screenshot from Performance Art/Movement Meditation Film (March 2022)



Figure 51. Phase II Practice: Screenshot from Performance Art/Movement Meditation Film (March 2022) [*Listen to Audio Excerpts of Collaborators' Words*](#)

In Phase II, the research processes expanded beyond my usual solo artistic methods into something more open and co-creative, echoing the sentiments of crip artist and scholar Petra Kupperts above. Though much of my research time remained as an exploratory solo practitioner, the dynamic inclusion of female endo sufferers as collaborators amplified the embodiment of feminist, crip, and improvisational perspectives introduced in Chapter 2. For instance, feminist scholar Nicola Harding indicates that meaningful and transformative research can truly only happen in collaborative research, further emphasising that ‘collaborative research with marginalised groups holds promise for more democratic forms of knowledge production when performed within feminist principles’ (2020: 12). Additionally, incorporating other women’s stories and inputs in this project not only reflects distinctly feminist aspirations, but also aligns with critical disability goals ‘to retrieve dismissed voices and misrepresented experiences’ (Garland-Thomson 2005: 1557). Lastly, exploring and foregrounding a range of endo stories represents the ‘multiple realities’ of the disease (Groat & Wang 2001; Guba & Lincoln 2005), promoting overlapping feminist, crip, and improvisational tenets such as inclusivity, democracy, and the celebration of diversity, as mentioned in Chapter 2.

As Chapters 3 and 4 delineate, the entwining of independent art-making processes with interactive dialogues emerged as the cornerstone of the research's methodologies, yielding fresh insights and articulations surrounding female pain experiences and endo-centric painscape practices. These emergent revelations — such as embodied agency (non-vertical embodiments of pain; spatial trajectories with lower orientations; and energies of recuperation); time (creative engagement with scars, memory, crip time, or interruption); in/visibility (the co-existence of dualities and binaries, the split self, pain's palette) — formed the foundational elements of netherness's materialising architecture. Importantly, as mentioned above, in this part of the research, introducing the methodological thread of collaboration elicited new thinking around 'witnessing' and its relationship to validation, which will be further unpacked in the Conclusion chapter in relation to the lens of *artivism*. In conjunction with the theory developed in Chapter 2, the modalities and body of work from Phase I and II functioned as a compass for Phase III of the research: the development of *Nether Space(s)* as a final multilayered endo-centric painscape consciously instituting netherness practices and exuding netherness as an aesthetic.

CHAPTER 5: PHASE III: CULMINATING PROCESSES & ARTISTIC OUTCOMES

Introduction: The Reverberations



Figure 52. Phase III Research: Studio at the Gibbes Museum of Art in South Carolina (August 2023)

This chapter provides a comprehensive exploration of Phase III (March 2023-August 2023), wherein the research's creative practices and artistic outcomes evolved to the point of culmination. This phase transpired in an intensive three-week artistic residency at the [Gibbes Museum of Art](#) (Charleston, SC, USA) and an earlier performance at the [Medical University of South Carolina](#) (MUSC). During this time, the quest to unveil endo's intricacies persisted through a process of fusion and layering. The insights that had emerged through the research framework discussed in Chapter 2 and the research practices revealed in Chapters 3 and 4, were woven more intricately into the fabric of this phase.

While the concept of netherness had begun to take shape in Phases I and II and its evolution continued, it was in this culminating creative period that its influence was more consciously harnessed. Private experiences expanded into the public space, increasing visibility of the otherwise hidden world of endometriosis while the ongoing collapse of the space between 'I' and 'them' continued to form a more expansive and inclusive 'we'. Channelling embodied wisdom through various mediums and using the developing praxis of netherness, testimonies of pain evolved into celebrations of body and identity diversity.

A significant portion of this chapter is dedicated to describing Phase III's increasingly nether-informed and informing creative practices and the resulting hybrid performance/exhibition piece entitled *Nether Space(s)*. *Nether Space(s)* manifested as a rich tapestry of various visual, audio, and movement painscapes united into a single universal painscape through the act of performance. These distinct painscape outcomes will be shared through relevant video, text, and imagery and include: a collection of six poems; six large abstract expressionist painting performances and paintings (six short films depict their live creation); six original costumes generated through the painting performances; an original sound-score incorporating poetry spoken by collaborators as well as audio clips from two

medical professionals; and notably, movement expression performed by three dance artists. These artists are: Jessie (who is a collaborator and introduced in Chapter 4), Jordan Maria (Charleston dance artist), and myself.

Describing the activities, processes, and outputs in detail is crucial to this research as it provides a comprehensive understanding of how creative practices engage with and represent endo experiences. Detailed descriptions provide deeper alignment with underpinnings of painscapes. For instance such granularity offers: a transparent articulation of the methodological framework highlighting specific ways in which endo pain is both enlightening to, or transformed through, creative process; foregrounding of the body as a central narrator (Tarr 2017; Gonzalez-Polledo & Tarr 2018); and a thorough comprehension of the embodied nature of the research. These descriptions also reinforce the collaborative and iterative nature of the research, aligning with feminist and crip methodologies by emphasising transparency, reflexivity, and the co-creation of knowledge. This distinct method is integral to the research's disruption of traditional paradigms and fosters of a deeper engagement with the embodied realities of endometriosis. Such an approach validates the lived experiences of endo sufferers while challenging conventional representations of pain and illness, thus offering new pathways for understanding and expression.

Subsequently, I discuss this phase in terms of the thematic threads that have emerged in the previous chapters, focusing again on reflections around embodied agency, interruption/crip time, and in/visibility in both expression and representation. This chapter also hints at substantial underlying activist and social justice components of this, and other, painscape work. Moreover, the various creative outcomes presented here (both the processes and artworks themselves) will be further unpacked in conjunction with a conceptual discussion of netherness in Chapter 6.

The Practices & The Outcomes

Kinaesthetic Painting Practice

In the studio space at the Gibbes Museum, as well as at MUSC, I felt tangibly supported by the research's artistic history. With the notion of witnessing and the cultivation of radical empathy at the forefront of my mind (as mentioned in Chapter 4), I introduced a new modality into the research that involved the inclusion of live audiences: solo body painting performances (which I also refer to as kinaesthetic painting performances). Blending my practices of movement meditation and body painting (modalities introduced in Chapter 3), this practice was characterised by improvised movement, gesturing, and mark-making as my whole body interacted with acrylic paint. In a series of six solo performances, six large (4' x 6') acrylic, abstract expressionist paintings were created in this manner. The performances and the paintings themselves aimed to express both a collective endo experience and pay homage to the individual narratives and identities of research collaborators, including myself. The pain experiences of the five women, along with my own, were embedded in the physicality and intentions of the work, in dialogue with the artistic materials.

In contrast to earlier paintings, these works more deeply married visual art and live performance elements with the inclusion of an audience witnessing their genesis. The first solo painting performance transpired outside of this public facing museum context. In March 2023, I had the opportunity to present to medical students and residents at MUSC as a part of a ‘Communicating Compassion’ seminar series through its Medical Humanities department. The five remaining painting performances occurred over the first two weeks of the residency in the museum for intimate studio audiences. Significantly, performing in the medical education context was a vastly different experience from the public museum context and these differences will be reflected upon in later sections.

In a departure from Phase I and II, as well as my pre-existing live art repertoire, I made a conscious choice not to stylise or hyper-feminise my appearance. The same level of visual discord and juxtaposition in relation to deconstructing norms or ideals around femininity or body normativity from the first two phases (discussed in Chapter 1) was not employed in the costuming approach to *Nether Space(s)*. Unlike the previous experimentations (mentioned in Chapters 3 and 4), I refrained from using costuming or masks to distort or disguise the body and/or identity. Instead, I opted for a range of nude-shaded or black, form-fitting bodysuits that cultivated openness and vulnerability between myself and the audience by simply emphasising the body’s form without additional elements of performativity. The bodysuits were transformed through the practice and became artful memorials of each collaborator’s pain. In another iteration, I hope to revisit the costuming using masks, props or materials (particularly red yarn) in connection to embodying various states of netherness.

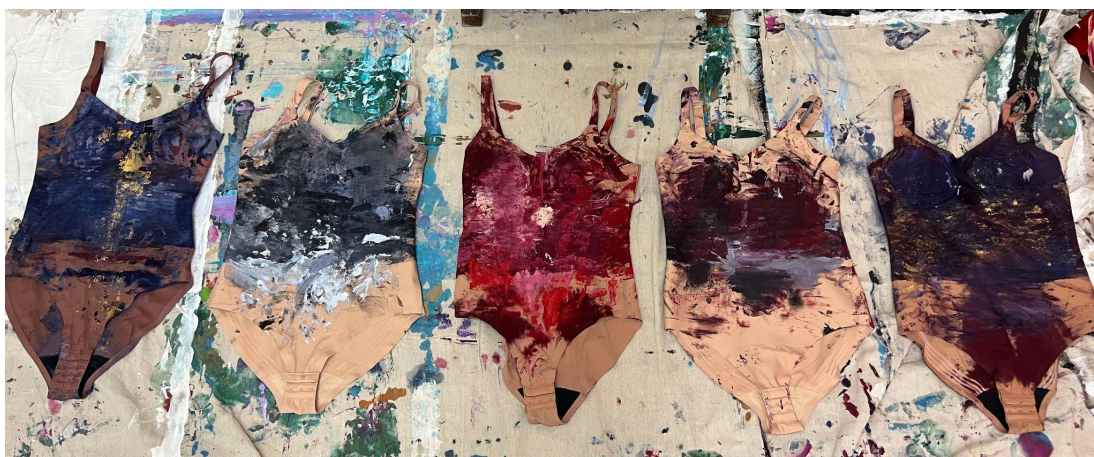


Figure 53. Phase III Artefacts: Bodysuits transformed through live performances (August 2023)

Though every performance was improvisational, each began with a carefully orchestrated sequence of steps, imbuing the occasion with a sense of ritualistic reverence. The process commenced by revisiting writing and artistic works that originated in specific collaborator exchanges. Then, rooted in the impressions of these exchanges, I intuitively selected colours symbolising both the collaborator’s essence and her pain story. Next, the coordinating poem, an additional concrete tribute to the individual, was then inscribed onto the blank canvas just prior to the performance. Although these words would ultimately be covered with paint, they left an energetic footprint akin to pain’s residue

(first mentioned in Chapter 3). To ensure the poems remained accessible, they were also rewritten on the painting's other side, allowing audiences who did not attend the live painting performance to connect the words with the abstracted visuals.



Figure 54. (above) & Figure 55. (below) Phase III Practice: Photography of initiation of first Kinaesthetic Painting Performance (August 2023)



In the performance space, after the audience members settled, I typically offered a brief introduction to the research and myself. Then, I approached the wooden canvas, pausing to connect to breath and intention. Upon my signal, the music commenced. I would then invite pain into the moment, carefully and protectively, and by doing so, I assumed control over it in a way I might not usually be able to in the midst of suffering.

While no formal movement score was explicitly delineated during these painting performances, in this time period I was concurrently immersed in both the continuation of movement meditations as well as the development of choreography for *Nether Space(s)*. Within this ongoing movement research, I further delved into the concept of non-verticality previously introduced in Chapter 3, and began to dynamically investigate postures, trajectories, and other movement qualities that I perceived as emblematic of netherness. Some of these included an increased use in gestural expression; floor-work;

stillness; slower pacing; chaotic bursts; and engagement with scar imagery. This research informed the movement improvisation in the painting solos, fostering the development of a flexible vocabulary that I iteratively explored. Conversely, the expressive explorations of the solo performances reciprocally enriched the ongoing movement developments.

Leveraging an improvisational presence and impulses (defined in Chapter 2 and illustrated in the practices of Chapters 3-4) in my endo-centric and increasingly nether explorations, I danced on and around the canvas, in and out of paint. In the throes of these solos, as paint accumulated on my skin and on the wood, all the layers — of self, of research, of artistic practice, of endo — seemed to collide, mirroring the intricate entanglement of endo within internal spaces. Much like the way endo tissue hybridises the body's interior, creating scar tissue and adhesions, the convergence of these layers in my creative process symbolises the complex interplay between personal experience, academic inquiry, and artistic expression.



Figure 56. Phase III Practice: Closeup Screenshot from Kinaesthetic Painting Performance (August 2023)

I recalled Toby's silent screams through facial expression and gesturing. I mimicked Mei's drawings, cradling myself in a slumped position. I slowed down, offering my body the rest that Danielle could not grant herself at a family celebration. I covered my left eye thinking about the stabbing ocular migraines of which Chelsea and I both suffer. Upon hearing Jessie's voice recite the word 'darkness', my body ceases movement. I carved lower spaces with my pelvis, embodying pelvic floor dysfunction and responding to the word 'aching' sketched repetitively on a canvas that I caught sight of during a performance. I arced my limbs in response to the abstracted markings that appear on one of the preliminary paintings. I aggressively pulled my fingers down the canvas, directing the paint and sand into specific patterns; the action evoking not only the dragging feeling felt in the uterus during menstruation, but also, echoing the disruptions of the red yarn spun around the studio and in performative rituals. Indeed, our bodies' stories seemed to reverberate fluidly in and through each improvisational act. While the pre-performance rituals and music score remained consistent, each performance and resulting painted artefact were unique — representative of the overlapping

improvisational, feminist, and crip strategies mentioned throughout this thesis like spontaneity, adaptability, and attunement to body, environment, and other bodies.



Figure 57. Phase III Practice: Screenshot from Kinaesthetic Painting Performance (August 2023)

Following every performance, I engaged in a dialogue with the audience and then showered for extended amounts of time in order to remove the paint remnants from my body. Interestingly, these seemingly mundane post-performance moments served as built-in reflexive breaks allowing for immediate consideration of creative and other personal revelations from the performances. Some of this thoughtful introspection impacts the ensuing architecture of netherness and can be found embedded in the reflective writings from this period, many of which are contemplated with discourse later in this chapter.



Figure 58. Phase III Practice: Post Performance Self-Portrait (August 2023)

Significantly, for the performance of *Nether Space(s)*, the six paintings were placed in a circular formation, creating an enclosure in the rotunda space of the Gibbes Museum. In the beginning of the production, the audience was invited to freely move around the structure, viewing and interacting with the visual piece on the front and the poetry written on the back. The arrangement created a theatre-in-the-round setup wherein the three performers (collaborator Jessie, Jordan Maria, and myself) performed in the central space with the audience surrounding us from all directions. The paintings felt alive, imbued with the residue of both pain and performance. Additionally, these six painscapes appeared to encapsulate the essence of each collaborator, bearing imprints of our individual endo-journeys as well as our co-creative duets. As if spectral witnesses, these painscapes simultaneously haunted and anchored the space for the audience and performers — ostensibly enveloping us in protection and reminding us of our own strength, despite the challenging subject matter.

In the section to follow, I invite the reader to witness the solo performances through video excerpts ([full video raw footage is available in Appendix A](#)) as well as the resulting visual painscapes.

Painscape Portfolio: Kinaesthetic Painting Performances & Artwork

I. MEI

Excerpt of Performance: <https://www.youtube.com/watch?v=iixOkeYV7YU>

Location: Medical University of South Carolina



Figure 59. Artistic Outcome: Painting titled *Mei* (March 2023)

II. CHELSEA

Excerpt of Performance: <https://www.youtube.com/watch?v=td4R2-UK3q8>

Location: Gibbes Museum of Art, South Carolina



Figure 60. Artistic Outcome: Painting titled *Chelsea* (August 2023)

III. TOBY

Excerpt of Performance: <https://www.youtube.com/watch?v=oBMt2IwL3Ro>

Location: Gibbes Museum of Art, South Carolina



Figure 61. Artistic Outcome: Painting titled *Toby* (August 2023)

IV. JESSIE

Excerpt of Performance: <https://www.youtube.com/watch?v=3fkC0aaFqEw>

Location: Gibbes Museum of Art, South Carolina



Figure 62. Artistic Outcome: Painting titled *Jessie* (August 2023)

V. DANIELLE

Excerpt of Performance: <https://www.youtube.com/watch?v=eaGVn-YJvL4>

Location: Gibbes Museum of Art, South Carolina



Figure 63 Artistic Outcome: Painting titled *Danielle* (August 2023)

VI. KATE/NANCY

Excerpt of Performance: <https://www.youtube.com/watch?v=IDKTh1fbsmM>

Location: Gibbes Museum of Art, South Carolina



Figure 64. Artistic Outcome: Painting titled *Kate/Nancy*; (August 2023)

Written & Sound Practices

The embodied writing practice persisted in a style and approach largely consistent with its introduction in Chapter 3: reflective writing and critical theorising were utilised to delve into lived experiences and practices. Nevertheless, poetry remained the most personally fulfilling medium for expressing both invisible and visible suffering, disorientation, or disruption caused by endo. In tandem with the movement research and prior to the kinaesthetic painting performances, I engaged in written reflection inspired by the journeys of my collaborators (as divulged in Chapter 4). This reflective process involved writing about their individual experiences in relation to my own, aiming to discern and analyse shared themes and divergences (some of which are shared in Chapter 4). Through iterative cycles of written reflection and movement meditations, I meticulously identified specific moments or experiences that recurred in my conscious and subconscious expressions. Following months of subconscious and conscious incubation, the creation of a single poem honouring each collaborator emerged at the start of this research phase. The poems seemed to be expelled from my bodymind in a burst (not dissimilar to the art-making bursts mentioned in relation to crip time in Chapters 2 and 3), emerging in windows of opportunity, clarity and flow. These six poems, shared subsequent to this section, mark a profound synthesis of lived experience, narrative, reflection, and artistic expression. The poems infused each painting with heightened intentionality, serving as sources of meditation and contemplation before embarking on each solo performance.

After completing the six written painscapes, I extended invitations to the collaborators to record themselves reciting their respective poems. With the exception of Toby, who was unable to fulfil this task at the time, they promptly provided their recordings. I recorded myself reciting Toby's poetry. I subsequently forwarded the audio files to Marcus Amaker (<https://marcusamaker.com/>), Charleston South Carolina's inaugural poet laureate and a respected composer (further details regarding his compositions are elucidated in Chapter 6 in relation to netherness). Collaborating remotely, Amaker and I conducted several virtual meetings and engaged in numerous email exchanges to deliberate on the musical conceptualisation of *Nether Space(s)*. I delineated the envisioned ambiance of netherness and its intended musical embodiment, characterised by elements such as intensity, dissonance, cyclicity, chronicity, and moments of disruption. Amaker proposed several compositions, from which we selected pieces for integration with the spoken poetry. Following this, I undertook the task of editing the final structure, ensuring seamless transitions between each piece to effectively epitomise and propel the essence of netherness.

The final component of the sound-score entailed the incorporation of audio recordings featuring two medical professionals, namely Dr. Daniel Kort (<https://newayfertility.com/team-member/dr-daniel-kort/>) and Dr. Amir Marashi (<https://nycgyno.com/amir-marashi-md-facog-facs/>), who have respectively served as my current and former doctors. I tasked each of them with recording their perspectives on endometriosis and encouraged them to discuss my medical history. Consequently, their monologues centred on themes such as endometriosis, infertility, and their shared experiences in

providing treatment. Despite their efforts to convey empathy and connection, the language naturally assumed a more medicalised, sterile, and unilateral tone. Their words, strategically positioned at the outset of the sound-score, serve to juxtapose the poetic and musical elements, offering a stark contrast between clinical discourse and the artistic expression of medical narratives.

I encourage the reader to engage with not only the text of the poetry as shared below, but also, with its animation within the most recent version of the sound-score.

Audio Links:

Track 1: https://drive.google.com/file/d/1ljslS8pM3fqIkdOBvkg5GufhIXzxxPv5/view?usp=drive_link

Track 2: https://drive.google.com/file/d/1ce-ydIhnmexSeYioTRrCWbeLEUKbHxo/view?usp=drive_link

Painscape Portfolio: Poetry**I. Under the Blanket (Mei)**

You grip
 The ratty blanket.
 Knit by your
 Grandmother's worn hands.
 No longer in its prime.
 Made with and for
 Warmth and delight
 Folly and beauty.

You lie in bed
 With memories
 Of her
 Floating
 While cysts and dreams of motherhood
 Are bursting.

You caress the faded colours.
 Wrapping your limbs
 In softness.
 Concealing the ghosts of incisions,
 Undoing
 Season(s) of pain.

You pray the yarn
 May act as a conduit
 For healing and relief.
 As the shivering
 Intensifies,
 So do the invocations.

You plead
 For peace again
 During flickers
 Of disarray and isolation.
 This old quilt is your
 Soul defence.

You awake
 On the cold bathroom floor, again.
 Cradling the blanket and
 The former patches
 Of levity
 In your innocent youth.

II. All Fine Here. (Chelsea)

Collapsing
In a slow
Tangled twist
Bones and flesh
Melted in a pile
On the corner
Of Sullivan and Spring.
It's fine.
I'm fine.

Reaching upward
Gracefully
With expediency
Towards a place
Of unravelling.
Wringing out the tears
From fresh scars.
It's fine.
Really, I'm fine.

Sinking feelings arise
From stabbing anomalies
Originating
In the pelvis
Surfacing brightly
In my pulsating
Left eye.
It's fine.
She's fine.

Wearily cycling
Into the dawning light.
Craving the dependability
Of the grid.
Seeking
Distance from
Flaring wounds.
We're fine.
Really, so fine.

III. Sewn Back Together (Toby)

No one paid a lot of
 Attention to IT.
 IT paid far too much
 Attention to her.
 She shoved
 The wet washcloths
 Into a sobbing
 Mouth,
 Wearing her Sunday best.
 Her screams were
 For all and no one
 To hear.
 She would not
 Make it to church
 That lovely May day.

What was done
 By IT
 Was undoable.
 Unpretty.
 No matter how many
 Years go by
 IT lives very near to
 The mind's eye.
 Because IT
 Robbed her
 Body.

Of giggles
 And lightness
 Of cradling
 And softness.
 Of glory.
 IT stole
 The possibility
 Of an expanded
 Breast.

Somedays
 She still holds
 Her heavy head
 And reaches
 For the pills.
 The painting
 Was steeped
 In deep redness —
 An all too familiar
 Shade of IT.
 She asked,
*What colour are you going to use
 to put yourself back together?*
 We looked at
 Each other
 Dumbfounded.
 We might discover
 An answer
 One day.

IV. The Pain Vacuum (Jessie)

Darkness.
Where have all
The stars fled to?
Inside my belly
They used to
Shine bright.

Numbness.
Has the joy
In your eyes
Vanished?
We are blinded by
Falsehoods.

Nothingness.
Have you heard
The sound of silence?
Her pelvis
Rocks to its
Rhythm.

Blackness.
Can the colours
Of rainbows
Be captured?
Beauty seeps
Into the fissures
Of my cracked
Foundation.

V. Down, Wake, Blue, Weep, Love
(Danielle)

The needles
 Pushed deep into
 Her brown skin.
 Injecting hormones
 And depositing
 Knots of fear.
 Jab after jab
 She saw clouds
 Swirling.
 The rain poured,
 Down
 Down
 Down
 All fall down.

The storm
 Assaulted the entire home
 Suddenly,
 Fiercely.
 Leaving nothing but
 Ash
 In its wake...
 Wake

Wake
 Wake
 Wake up!

The destruction
 Is far-reaching.
 Inescapable roadblocks.
 Mind blocked,
 Body blocked,
 Spirit rocked.
 Every single
 Nook and cranny
 Battered.
 Black and blue
 Blue
 Blue
 Blue
 The deep, dark blues.

The lone dream
 Splintered
 In the ominous sky.
 A million pieces of

Hope
 Disintegrating into
 Dust.
 Under the carpet
 It was swept...
 Sweep
 Sweep
 Sweep
 Weep.

The heavy fog
 Lingers.
 Lifting
 Every so often,
 To reveal
 A Phoenix rising.
 In tandem,
 Sunshine arrives,
 The dog smiles
 Gifting unconditional love.
 Love.
 Love
 Love
 Love...

VI. Red All Over (Kate)

Black and blue stomach.

Black and blue ovaries.

Black and blue veins.

Black and blue pelvis.

Black and blue spine.

Black and blue ego.

Black uterus, blue heart.

Black and blue and red all over.

Movement Practices (Choreography, Improvisation, Performance)

Leading up to the residency period, the independent and co-creative movement meditations and performance art explorations discussed in Chapters 3 and 4 continued. At this point in their evolution, the modalities remained consistent, yet over time, as the concept of netherness deepened through the live painting practice, the movement became more refined and specific. Specifically, I shifted my art-making to more intentionally reflect and explore the arising themes associated with endo-centric spatialities, temporalities, atmospheres, and impulses. These themes, which were ultimately the preliminary strands of netherness included: fostering embodied agency (challenging internalised ableist or gender norms through manifestations of crip resilience, crip time, or nonlinear and abstract narrative); disrupting ‘normalised’ temporalities or spatialities (through alternative pacing and rhythms or by embodying dissonance, liminality, or pain through non-verticality); or the expression and representation of the invisible (externalising the internal and materialising the invisible by using scar poetry and scar motifs as impetuses). Upon receiving the final sound-score, the movement was distilled into preliminary sections of choreography and improvisation.

Having established a loose structure and movement score for *Nether Space(s)*, I proceeded to conduct a series of remote rehearsals. Collaborator Jessie (previously introduced in Chapter 4 as a dancer) and Charlestonian dancer Jordan (notably without endometriosis) participated via Zoom meetings and instructional videos. These virtual sessions prioritised choreographic development and the expansion of improvisation prompts centred around the concept of netherness. Additionally, the rehearsal series provided an opportunity for familiarisation with the sound-score.

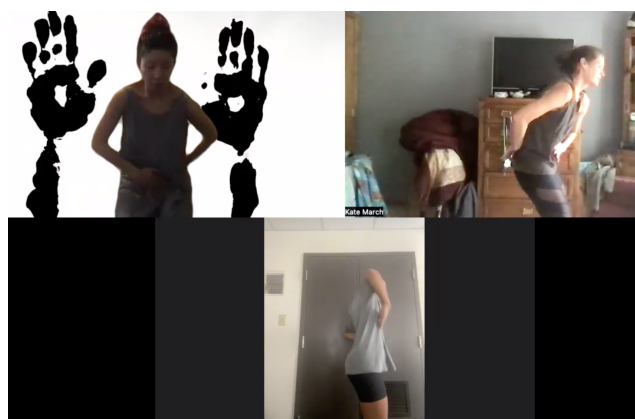


Figure 65. Phase III Practice: Screenshot from Zoom Rehearsal (May 2023)

The process of remotely developing, teaching, and learning the movement vocabulary posed challenges, given the embodied nature of this research. However, throughout these sessions, the exceptionally skilled artists acquired a foundational understanding of select choreographic and improvisational elements and developed an appreciation for the role of the score in shaping the overall performance ambiance. Despite the prolific movement research and development, the choreography and improvisation scores were only fully realised when our three bodies convened in the same physical space. This convergence occurred over the course of a week-long intensive at the

Gibbes Museum which followed the completion of the series of performance art solos. In that period of time, I used the mornings to solidify vocabulary or improvisation sections while I would teach the material to the group in the afternoons, relaying with an attention to conveying the essence of netherness.



Figure 66. Phase III Practice: Screenshot from Hybrid Rehearsal (July 2023)



Figure 67. Phase III Practice: Screenshot from Rehearsal Video at the Gibbes Museum (August 2023)

Striving to maintain a collaborative approach to the research, the dancers' perspectives, movement explorations, and insights were folded into the choreography in a similar manner to the endo collaborators' iterative feedback loop. The dancers' own personal embodiments of suffering, courage, isolation, and healing became core to the production and the realisation of netherness. The force of our collaboration surfaced not only in the delivery of the vocabulary, but also, through the vulnerability the engagement with netherness seemed to evoke. In the ensuing writing I describe the performance score, while the film documentation serves as a visual reference of such (video links provided below). The manifestations of netherness in this layer of *Nether Space(s)* is more fully addressed in the subsequent chapter.

In the development of *Nether Space(s)*, particularly through the body's own storytelling, the real and the abstract; internal and external; and inexpressible and expressible collide. Dualities or binaries that seemed to emerge in the endo bodymind — like ability and disability; self and other; individual and collective — were acknowledged, embodied, deconstructed, and merged. Likewise, the art-forms of dance, painting, poetry, and music coalesced, birthing an alternative narrative format for representing otherwise inexpressible or invisible (medical) sensations and experiences.

I encourage the reader to engage with the video of *Nether Space(s)* along with the score below.

Painscape Portfolio: Nether Space(s) Performance

Performance Video Edit: <https://www.youtube.com/watch?v=dXJ5yGPDQG8&feature=youtu.be>

Raw Footage Excerpts (to obtain a sense of liveness): [APPENDIX B](#)

The Score: This section denotes how each performance segment was arranged musically and visually.

I. Past Lives Haunt Us

The experience commences with the playback of recordings featuring the physicians referred to above. I enter the space, allowing the words to permeate through me, maintaining a composed demeanour despite the stark reminders of my personal struggles voiced through clinical discourse. Pacing and engaging in brief yet emotionally charged eruptions of movement, I present a contrasting physicality to the formal language of the audio. This contrast problematises the conventional mode of spectatorship and expression and also merges narrative and abstract. This introduction, characterised by the co-existence of opposing energies, serves as an invitation to the audience, encouraging them to broaden their perspectives and embrace an alternative way of understanding — an existence within a less dichotomous realm, a nether space. ([Appendix B](#) Video Link 1)



Figure 68. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023

II. Darkness

The musical score persists with verses from Jessie's recorded poetry echoing throughout the space. This prompts fellow performers to converge in the centre where we immerse ourselves in the ensuing score: a dynamic interplay between structure (choreography) and spontaneity (improvisation). The initial segment, titled 'Darkness' abruptly unfolds with an intensity — an *interruption* — designed to evoke immediate uneasiness among the audience. This section encompassed an explosive movement vocabulary embodying the violence of severe pain as well as the negative consequences of medical gaslighting. Energetic solo improvisations within 'Darkness' served as poignant expressions of each

dancer's personal revelations pertaining to pain, womanhood, and uncertainty. The unpredictable and assertive rhythms in the accompanying music synchronise with the execution of movements, creating an atmosphere of anxiety and tension. As the dancers shift spatially from the centre to the aisles, the closeness between performers and audience intensifies, simultaneously drawing increased attention to the additional entities in the space — Jessie, Toby, Chelsea, Mei, Danielle, and Kate/Nancy (the paintings). ([Appendix B](#) Video Link 2)



Figure 69. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023



Figure 70. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023

III. Scars

Transitioning into the subsequent section, ‘Scars’, the dancers united for the first time, with fingertips touching in a display of solidarity. Additionally, movements fluctuated between unison and individual expressions, as performers collectively wrestled with pain and explored the externalisation of pelvic turmoil. Amidst the torments inflicted by pain, reparative movements and energies oscillated. For example, in each collapse, as bodies gradually approach the ground, quests for comfort, acceptance, and peace become evident. While non-vertical or supported embodiments like slumping, collapsing,

or indeed horizontality demonstrate crip resilience, the relative brevity of such establishes an incompleteness in recovery and an overwhelming sense of relentlessness and interruption.

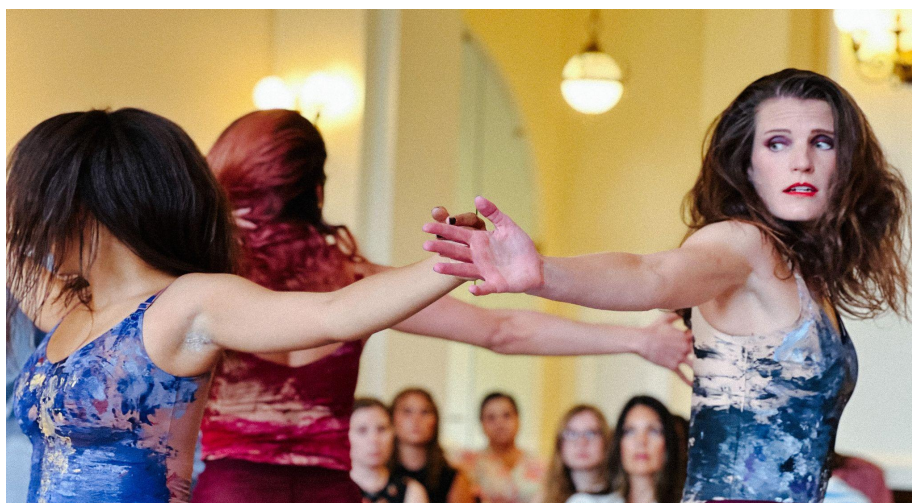


Figure 71. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023

Apart from the choreographed vocabulary, performers are directed to visualise wrapping, unwrapping, and tangling invisible red yarn throughout the space, over scars, and around bodies, while never reaching full verticality in moments of improvisation. These intuitive and gestured imaginings yielded what an audience member described as a ‘suturing’ motion, among other motifs conveying concepts of brokenness, wholeness, and healing. ([Appendix B](#) Video Link 3)

IV. She’s Fine/Warmth

The fourth section, ‘She’s fine/Warmth’, prioritises the distinct spatial trajectories and embodiments of an endo body’s reality, committing to a nether body language of pain. As alluded to earlier in the discussion, these nuances often manifested as an embrace of non-verticality and a distinct resistance to uprightness (explored further as a strand of netherness in Chapter 6). Initially, the ‘She’s Fine’ segment commences with a tense yet relatively calm choreographic pattern focused on exploring the possibilities of beauty and multiple meanings within a slumped or stooped-over posture. Repeatedly, the dancers lunge slowly in different directions and almost violently drop their torso over following the dominant leg. As if in a state of surrender, as the torso drops, the arms and head hang heavy in a bow bringing them closer to Earth. Following each lunge, the extended straight leg is dragged back towards the centre of the body in an effortful motion. In this embodiment, the surrendering bodies, caught in a limbo, are simultaneously fragile and unbreakable.



Figure 72. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023



Figure 73. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023

The ‘Warmth’ portion incorporates an improvisation prompting the performers to descend into deep second-position postures, summoning a warrior mentality. Akin to the previous improvisational interlude, this structured spontaneity is driven by scar imagery and scar poetry (inspired by Petra Kuppers as discussed in Chapter 3), as well as war metaphors — a common tool used in the verbal communication of endo pain (Bullo 2020; Bullo & Hearn 2021). Preparing for battle, and with slight torso slumping adding to the existing grounded-ness of the posture, dancers rapidly tap the visible and invisible scars of their bodies, physically and metaphysically acknowledging the body’s history. Following these revelations and iterations of resilience, the dancers once again returned to embodiments which convey the sense of capture and torture instigated by endo’s mayhem. Literally becoming stuck in place and remaining in the warrior postures, the only movement that can be

realised is through rhythmic body isolations of hips, shoulders, hands, and pelvis. As the improvisation progresses, driven by the emotion in Chelsea’s delivery and the underlying edginess in Mei’s tone, the momentum and chaotic energy continue until depletion is reached, and horizontality is fully realised (netherness in terms of energetic and temporal shifts is elaborated upon in Chapter 6). ([Appendix B](#) Video Links 4 and 5)

V. Down Down Down

Transitioning to prone or supine positions on the floor, the final two sections, ‘Down Down Down’ and ‘I am Broken and I am Whole’ commence. The dancers recuperate in stillness as Danielle’s voice marks the performance’s closing chapter. This position provides the dancers with respite before the final improvisation and choreography. Lying down for an extended time could also be interpreted as exhaustion, overwhelm, or catatonic grief — common bodymind states referenced in my collaborative exchanges and most recently experienced for me in two consecutive IVF failures. Whether the dancers succumb to or embrace stillness as a form of crip resilience (defined in Chapter 3) is purposely unclear. After a few minutes, slow movements are resumed and dancers lift one another back to more upright postures.



Figure 74. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023

‘Down Down Down’ is wholly improvisational with more devoted contact and weight-bearing exchanges between performers, representative of the cultivation of a support system. Despite undertones of grief or sorrow, this segment prevails in exemplifying the transformative coping power available in human connection, hope, and love. ([Appendix B](#) Video Link 6)

VI. I am Broken. I am Whole.

Finally, the repetition of the word ‘love’ carries the audience and dancers alike with some lightness into the end of the piece — an embodied declaration of ‘I am Broken. I am Whole’. The soulful and

beat-heavy musicality inspires, perhaps, the most virtuosic, full-body choreography. The women move synchronously, melting their brokenness and wholeness into a display of embodied juxtapositions: fearful and fearless; dark and light; frustration and acceptance. Ultimately reverting back to more gestural choreography, the closing repetitious vocabulary portrays a profound spiritual entreaty for peace. A gradual descent, eventually culminating in the purity of a child's pose, seems akin to bowing in reverence to personal and collective suffering. In this final posture, the performance finds an unsteady resolution in a stillness encapsulating exhaustion, but also, hope and the celebration of transformation. ([Appendix B Video Link 7](#))



Figure 75. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023



Figure 76. Phase III Outcome: Screenshot of Filmed Performance *Nether Space(s)* - August 2023

The Culminating Reflections

The additional or developed creative elements of Phase III infused what felt like vitality, authenticity, and indeed, netherness into the creative process. These experiences and the resulting artworks provide opportunities for deeper introspection and analysis around some of the discourse and themes that

emerged in the previous phases. As such, this section will briefly disseminate Phase III through the lens of the conceptual or aesthetic threads introduced and reflected upon in Chapters 2-4. These ongoing reflections and analyses contribute to the theorisation and implementation of netherness.

For instance, in this phase, performer and audience liveness, as well as the presentation of painscape art in public or medical performance contexts, contribute to discussions around embodied agency, visibility, and representation. Moreover, the research's collaborative efforts, which were ripened through various layers of co-creation coming to fruition in this phase (audience interface, recorded poetry, movement research), reveal more insights around the thematic thread of expression particularly in relation to exploring audibility, visibility, palpability and witnessing marginalised bodies or invisible experiences. Further, lived experiences of interruption that transpired over the course of Phase III provided opportunities to expand the project's exploration of crip time and crip identity. These culminating contemplations along with those of Chapters 3 and 4, prime the reader for the final discussion around netherness in Chapter 6.

Witnessing/Collaboration

Throughout my decades of creating experiential live performances, I have consistently prioritised how both audience and performers engage with and experience my art. Interestingly, incorporating the concept of witnessing, as discussed in Chapter 4, through the merging of self and other in audience interactions, felt especially significant in the kinaesthetic painting solos and the performance of *Nether Space(s)*. In her exploration of trauma, bodies, performance art, and the ethics of seeing, trauma studies scholar Sophie Oliver-Mahler highlights various responses that the 'spectacle of the other's suffering' might evoke, ranging from disgust to pity to voyeurism (2010: 122). With the core strategies of adaptability, heightened awareness, somatic consciousness, crip time, and an underlying intuitive spontaneity, the research methodologies likely prepared me for a spectrum of responses to witnessing and being witnessed. In particular, the audience's presence, enlivened by proximity, was crucial in establishing a co-creative atmosphere that appeared to enable both co-witnessing and new levels of visibility, audibility, and palpability.

In general, I envisioned the audience as custodians of the space for both myself and, eventually, the other performers in *Nether Space(s)*. A critical aspect of this process was to avoid the distraction of feeling pressured to perform for or impress the witnesses, thereby disrupting the conventional contract between performer and audience (Albright 2018: 195). Viewing the audience as witnesses necessitated 'an attitude of inner openness' and a 'capacity for listening to oneself' (Albright 2018: 195). Similarly, akin to the collaborative exchanges, during moments of slowness or stillness in this practice and in the performance, I would reciprocally extend an outward focus toward the audience or the other performers, fostering an enabling presence and compassionate gaze, deeply attending to their bodies.

This contributed in part to the contrast between earlier visual art explorations and the physically larger painscapes of this phase. The kinaesthetic paintings seemed to encapsulate the collaborators' and my endo narratives in a visceral manner, pulsating with raw energy and emotion. This embodiment likely mirrored an intensified immersion in netherness and the heightened impact of a live audience who served as dynamic witnesses to testimonies of pain, suffering, hope, and endurance. The improvisational painscape practice, woven in communion with public witnesses, became a catalyst for co-creativity, agency, innovation, and transformation for both spectator and performer, and by extension, the collaborators.

One of the most inspiring audiences to perform for included a group of high school students participating in a social justice summer program. This particular painting performance, devoted to honouring Chelsea's experiences, seemed to epitomise seeing and being seen for me as a performer. In this way, the performance appeared to carve a 'space for the female subject as both embodied and active' (Oliver-Mahler 2010: 122). In the midst of performing, I observed many young gentlemen in the audience navigating their feelings surrounding a female body dancing with rawness and agency, using menstruation and pain as content, in an artistic setting. Imperceptibly yet internally disoriented by their energy, I began the performance somewhat reserved. Confronting the audience's initial uneasiness, my expressions naturally intensified in an effort to reveal my passion and conviction, then ebbed back into moments of surrender, gentleness, and self-care. In this ebb and flow, I danced with empathy and compassion for the audience: giving and receiving what I felt they needed emotionally and energetically to participate. In response to my empathy towards the 'spectator's discomfort' (Oliver-Mahler 2010), I observed body language shift into more relaxed states; eye contact steadied, no longer meandering towards peers; and snickering silenced giving way to connection.

A pivotal juncture of my kinaesthetic painting practice occurred while I was creating Jessie's painscape when the creative power within the live audience and performer exchange was distinctly unleashed. Amidst the creation of her painting, I turned my attention to another empty expanse of white canvas, my crimson-stained hands gliding languidly across its pristine surface. This spontaneous act unfolded as an unforeseen revelation holding profound impact, both for me and, as post-performance discussions revealed, for the audience. This occurrence underscores the inherent potency of affording individuals the space, time, and freedom to improvise together. It serves as a testament to our capacity for self-discovery and the resonating influence of such moments on others. The act and energy of witnessing becomes a conduit, transcending the boundaries of our bodies. The empowering intimacy between the audience and myself laid sacred ground for the liberation of pain, vulnerability, presence, and dignity in the performance's unfolding. This liberation was memorialised in the paintings themselves. Improvising with a live audience witnessing set up an environment of impulse and co-creativity resulting in special moments like the red hand imprints.

Feeling seen, heard, or felt by the audience in these acts of witnessing and co-creating lifted me through discomfort and fear associated with being so honest, raw, and open with expression.

Likewise, anchoring the improvisational impulses in the concept of *crip resilience* grounded me in the moment, affording reflective moments of pause inviting increased eye contact or more outward attention towards the audience. Many times, I sensed their uneasiness and ‘squirm’ factor as my body writhed or collapsed or my painted fists smashed down upon the canvas. In these cases, I persisted as confidently as possible, challenging able-bodied narratives by recognising the value in externalising the challenging and sharing uncomfortable parts of *endo* experiences.

Site/Context

Viewing performance as an exchange between witness and pain sufferer, it becomes clear that the performance space, context, and identities of audience members might significantly shape the ways that representation and visibility are realised. Relatedly, these contextual aspects of performance simultaneously impact how marginalised bodies/identities might use performance and pain expression as a means for reclaiming power and agency.

For example, the differing contexts of the *kinaesthetic* painting performances facilitated personal experiences of agency and empowerment through different pathways. but also shaped the trajectory of the creative process and the resonance of a *painscape*. The act of performing in a public art museum for a community audience markedly contrasted with the dynamics involved in presenting and creating within a medical education setting. Each of these contexts provides a distinct opportunity for shared experiences, the potential visibility of pain, and the prospect of personal transformation/*embodied agency*.

Performing in a public art museum setting, with a role as ‘visiting artist’, engaged a diverse community audience. This experience introduced a unique dynamic, emphasising the communal nature of the artistic encounter. Steeped in its own meanings, histories, and traditions, the museum site itself became a crucial element actively considered. On the other hand, the medical education context offered a different set of forces, involving engagement with medical students and residents. Here, the focus shifts towards the intersection of art, medicine, and education where compassion and the conveying of experience becomes a central aspect of the *painscape*. The backdrop of medical education, with its emphasis on scientific understanding and clinical perspectives, adds a layer of complexity to the presentation. The potential impact on the audience, composed of individuals immersed in the medical field, brings forth nuanced considerations. The distinctive influence of these varied contexts sheds light on the intricate interplay between performance site, audience as witness, and the realisation of *netherness* in a *painscape* practice.

In the performance/lecture in the medical education context, non-verbal, abstract creative expression, and narrative medicine merge to form a new mode of witnessing someone’s *embodied medical history*. After years of my pain being dismissed or minimised by medical professionals, in this space, future or current doctors describe my pain expression using words like ‘bravery’ or ‘strength’ or ‘enlightening’. It is surreal and emotional. Redeeming and raw. Within this unique context, I wonder:

is this a performance, mere reality; or a combination of both? Was the MUSC lecture hall serving as a stage or was it akin to an examination table or surgical theatre where I unveiled my innermost self to those in authority? Was this a moment of rupture where my body's truths, so often historically minimised, finally found resonance? The novel performance setting as well as hybrid format forced me to seek and realise presence, attunement, and impulse amid a disruptive internal landscape. Through this new context and improvising with such personal and visceral material, I experienced a heightened level of authenticity and sentience. Indeed, inviting vulnerability into the process gave me wings as an artist: an expansion of ingrained body language; the shattering of perfectionistic expectations; and the willing experimentation of new dynamics (reflected on in relation to netherness in Chapter 6). I productively fused my own physical, emotional, and psychological scars of endometriosis with impressions and narratives gleaned from other women through recurring verbal and nonverbal dialogues. Perhaps, in that space, my body articulated what words could not.

Over this research, visibility is implicitly applied in the expressive sense of externalising the internal — which of course supports representational visibility discussed above. Thinking about visibility in this sense for these contexts is especially relevant. For instance, several medical students described the tangles of red yarn in the videos and paintings as strikingly familiar, recalling pelvic adhesions observed during educational surgeries in medical theatres. This observation highlighted the intersection between medical and artistic representations of endometriosis, suggesting a shared engagement in revealing the hidden and often grotesque realities of the condition. The use of a specific colour palette, with red and black dominating, was noted by several observers. These colours were identified as anatomically accurate, reflecting the actual appearance of endometriosis lesions and chocolate cysts filled with dark, almost black blood. Such comments underline the importance of visual atmosphere in the research painscapes, which serve to connect the literal origins of pain in patients' bodies with their artistic representation.

The integration of these visual and poetic painscapes into medical interactions offers a novel way to attune medical practitioners to the lived experiences of their patients. By visualising pain and internal bodily experiences, these artworks provide an alternative means for patients to express what is often inconceivable through conventional medical discourse. This aligns with the theme of visibility, as these artistic representations make the invisible experiences of endometriosis sufferers visible, fostering empathy and understanding.

The five other solo performances and the final performance of *Nether Space(s)* at the museum were comparably vulnerable experiences which also facilitated agency for my body and assertion of my identity. In the Gibbes Museum, a public audience walked in and out of my dedicated studio space speaking with me about art and women's pain experiences. The museum, centrally located in a popular city in the American South, provided me access to a diverse population of spectators including local art supporters and novices alike. In the studio, where all bodies and identities are

welcomed into the space, artistic expression organically intersected with the realm of public advocacy.

For three weeks, this site transformed into a second home where I cultivated a sense of personal ownership. As a result of this, the space itself seemed to demand a more equalised relationship between the audience and myself, encouraging respect and attention from them as they bore witness to my art-making and my body's storytelling. Despite the subject matter which could be considered triggering, uncomfortable, or taboo, the majority of people attending engaged in the performance space with captivation, curiosity, and presence. In our post-performance dialogues, I was nourished by their feedback, emboldened by our conversations, and humbled by their praise.

Across most of Phase III performances, I felt seen, heard, and validated. Though I can only speculate about what other endo sufferers experienced, whether audience members or collaborators, some degree of embodied resonance was discerned. For instance, following the *Nether Space(s)* performance, the audience and performers reconvened at the transformed performance site for a dialogic exchange facilitated by MUSC medical humanities professor Lisa Kerr (<https://education.musc.edu/MUSCApps/FacultyDirectory/Kerr-Lisa>). In this newly altered space, we revisited our use of language, engaging in dialogue that perhaps allowed for new and different expressions.

Engagement with the overall production/exhibition was apparent through the dynamic dialogues that ensued. Some audience members, likely not suffering from endo, communicated a range of emotions they personally sustained over the course of the choreography, including uneasiness, tension, fear, hope, and frustration. Other attendees shared imagery or emotions they perceived from the choreography, like solidarity, womanhood, strength, courage, pain, or medical procedure depictions. Perhaps the most personally meaningful responses were delivered by several individuals, who verbally identified themselves as also having endometriosis. Some were emotional, wiping tears from their eyes and others verbally expressed gratitude for the sense of validation, resonance, and connection this artwork offered them. Many endo sufferers introduced themselves to me in the post-discussion time period, relaying their own stories of pain's chronic disruption using words like isolation, shame, and grief. In my exchanges with these kindred spirits, I perceived shared experiences of visibility, community, connection, and empowerment.

In general, sharing painscapes with the community as witness and welcoming discussion of endometriosis and creative process in an open public forum paved the way for authentic advocacy and education opportunities. In this context and through integrating post-performance discussion into the painscape format, conversations naturally delved into infertility, menstruation, women's experiences, chronic illness, disability, health inequities, creativity, and/or improvisation, topics not frequently encountered in such settings. The affirmative personal and social justice implications realised through this phase will be analysed in the concluding chapter of this thesis specifically in connection to activism.

Embodied Agency (Integrating Crip Time, Crip Resilience, Crip Futurity)

In this research journey, the interaction between my own physical experiences and artistic practices demonstrates how bodily realities can deeply shape and inform artistic practice and aesthetic outcomes. This interaction and research theme — focused on the creative manifestations of pain and its conceptual relationship to embodied agency — is best understood, in this phase, through the lenses of crip time, crip resilience, and crip futurity.

For instance, following the first Gibbes solo performance (*Chelsea* painted painscape), I tested positive for Covid while simultaneously learning that my second IVF cycle in three months had again failed to produce viable embryos. Due to my Covid diagnosis and the museum protocols, I was prevented from entering the studio for five days. This enforced hiatus which forced me to confront pain's unforeseen inconveniences and ability to disorient, compelled me to pause and recover; experientially highlighting crip time's emphasis on flexibility and slowness. This period in the research underscores the non-linear, adaptive nature of crip time and crip resilience, where my body's needs dictated the flow of activities. Eventually, with the support of acupuncture and therapy, the research resumed, with my acceptance that creating with real pain might offer catharsis for myself and a palpable expressiveness in the painscapes for others. Improvising with pain while intentionally engaging with the budding notion of netherness activated a deeper sense of self-care; empathy towards my five collaborators; and genuine embodiments of dissonance. This process may have influenced the audience's presence and attention, highlighting the interdependence of performer and witness within the lens of crip time or resilience.

The remaining performances at the Gibbes were not only physically challenging due to recovering from acute illness, but also emotionally raw. The performances brought the intense sadness and grief caused by endometriosis-related issues such as infertility, fatigue, and pain to the forefront. In the first post-Covid painting performance, honouring Toby, I engaged in deliberate acts of marking the body or canvas with paint using slower pace and gestural expression which introduced concrete moments of presence, recuperation, repose, pause, and comfort. These actions, embodied manifestations of both crip time and crip resilience, illustrate the adaptive strategies employed to navigate physical and emotional disruption and disorientation in performance. By demonstrating care for my body, I signified empathy and care for the collaborator's body and story, expanding the realisation of crip resilience.

The decelerations, subsequent dormancies, and associations of dissidence from these subdued energies were recognised in various dimensions of the artistry in this phase including poetry and music. In the score and written poetry, the haunting recurrence of words or phrases created arresting repetition. Caesuras fostered moments of pause, stuckness, suspension, and meditation, revealing a concealed, latent underworld of pain erupting to the surface. Similarly, gaps of silence or meditational whispers in the sound-score provided an escape from the intense throbbing and unpredictable rhythmic patterns, embodying the principles of crip time and resilience as well.

Likewise, the overall structure of *Nether Space(s)* was defined by its oscillation between choreographed movement vocabulary and structured improvisation, as well as solo and group work. This oscillation introduced inherent instability and fluidity into the experience for both performers and the audience. The dancers' bodies appeared to embody a perpetual state of transition, offering observers an unpredictable and, at times, viscerally disorienting journey. Qualitatively, the structure highlighted netherness's pursuit of in-betweenness or embodied dualness, alternating between or simultaneously realising technical movement and pedestrian gestures, frenetic and reparative moments, and isolation and togetherness. Within this implicit liminality, the movement expression focused on 'dwelling' (Albright 2018 as mentioned in Chapter 3) in and confronting dualities and dissonance related to the realities of endometriosis, reflecting the adaptive and fluid nature of crip time.

Relatedly, in the final production, the unmasked performers wore painted bodysuits that symbolised a departure from some of the more constructed or hyper-feminine aesthetic arising in Phases I and II. This was indicative of the research's embrace of an improvisational sense of free-spiritedness and spontaneity. These bodysuits, created through the body's interaction with paint, symbolically depicted the transformative power of self-expression in the context of pain. They embodied the memories and realities of pain, serving as poignant artefacts of both live performance and pain expression. This visual representation of pain emphasised the theme of visibility, making the internal and often hidden experiences of endometriosis sufferers accessible to the audience.

Moreover, the costuming reflected the non-linear and complex journey of healing, aligning with the concept of crip time, which challenges conventional, linear perceptions of time and embraces the fluid, adaptive rhythms dictated by the body's needs. In this sense, the performance highlighted the visible expressions of pain and underscored the importance of a flexible and compassionate understanding of time in the healing process. By embodying crip time and resilience, the performance envisioned a future where disabled individuals' experiences are centred, acknowledged, and valued, contributing to the broader discourse on crip futurity.

Conclusion: The Emergence of Netherness

The grace and technical expertises of my body are products of my spirit and soul and commitment to my artistic voice. They are in deep contrast to the disease and internal chaos that lives within me. Pain exerts control over me at times. Other times, in expression of my soul and spirit, I control and transform it into something different. The pain, my body, her body, over the course of this painting performance, we become art, we become hope, we become care.

We have agency. (Personal Reflections, August 2023)

Upon reflection, Phase III practices, artistic outcomes, and the performance of *Nether Space(s)* solidified certain conceptual and artistic threads emerging through an improvisational painscape practice focused on endo. The first thread, introduced in Chapter 3 and developed throughout the praxis, revolves around the theme of embodied agency. Embodied agency conceptually encompassed the endo body's navigation of pain and interruption which ultimately, using feminist/crip methodologies asserts identity, reclaims power, and seeks validation. Practically, this included affirming endo embodiments of pain or healing (crip resilience) and exploring nuanced relationality between self and other (collaboration and live audience) — which naturally shifted art-making and aesthetics.

The second thread focuses on the themes of expression and representation of the invisible. Conceptually, this involved amplifying female disability experiences like endo pain, interruption, or disorientation. In this project this was generally observed through the incorporation of personal narratives in poetry and other art forms and the witnessing of such by live audiences. Artistically, this translated into the externalisation of interior sensations and concealed experiences, explored through multidisciplinary, liminality, and nonlinearity to reveal endo's intricacies. Notably, as expanded in this chapter, the inclusion of live audiences foregrounds the implicit advocacy and activist dimensions of the research, particularly in relation to the role of witness and increased visibility.

The final strand, which intersects with both previous threads, concerns temporality and the endo body's non-normative experiences of time. Improvising with crip time, embodied memories, and the notion of split self reinforced the research's deep contemplation of liminality and dissonance. These embodied modes of being, thinking, and creating within interrupted or disoriented time weave into and out of the other two threads, but deserve their own distinct recognition.

This phase demonstrated a meaningful shift towards netherness, effectively embodying, honouring, and sharing the stories of endo warriors. Here, the accumulating conceptual and artistic thematic threads along with the methodological threads coalesced to form a nether painscape as well as the foundation for articulating netherness. Through its prioritisation of endo-centricities, *Nether Space(s)* unveils and defines a nether realm where the tensions of language, abstract expression, and the body's narrative overlap, forming a novel channel of creativity and a distinct mode of spectatorship in terms of female pain. In this world, the body's pains can emerge from and be received through a different, nether register — a landscape where 'some things can be left unsaid, implicit, homely' (Kuppers 2006: para 32) indeed, shared. Accordingly, netherness will be detailed in the subsequent chapter.

CHAPTER 6: NETHERNESS: AN ENDO-CENTRIC PRAXIS

Introduction to Netherness

...Look deep: deep under, below, is the underworld, the under-lit world of institutions of any kind, the wards and waiting rooms of hospitals, crypts, asylums— and the institutions of gendered, embodied difference much too quickly ordered into valid/invalid. In this void within, difference can flourish: that is the hopeful message... (Kuppers 2006: para 11)

Over the course of this thesis, the research's cumulative threads — methodological, theoretical, practical, and aesthetic — emerged and merged. Like the adhesions in an endo-afflicted pelvis, the research threads adhere to each other in such a sticky, intricate, interdependent manner, making their origins, intersections, and borders difficult to differentiate. In this chapter, collective insights are extracted and knit together to form the three strands of a netherness praxis.

In its developmental trajectory, netherness was initially conceived through the mobilisation of insights, elements, and themes derived from the endo explorations of Phases I and II, and it was then cultivated and actualised in the culminating practices and outcomes of Phase III. In this stage, it continues to evolve and mature in its articulation and realisation as a way of thinking and practising for others. The overall revelation of netherness is powerful in its ability to express female disability and pain experiences, as well as its potential to reimagine and reposition these experiences in both meaning and sociocultural representation. Akin to Kuppers's suggestion above, in this chapter's critical defining and unpacking of netherness, there is a hopeful message: despite its inexpressible nature, there are ways endo pain can be understood and articulated, differently.

Netherness prompts the 'shift in perspective' necessitated by intense experiences of interruption (in reference to Baraitser 2009: 73 mentioned in Chapter 2). In the realm of netherness, endo and its accompanying pain(s) transform from being perceived as mere sources of interruption, marginalisation, or disorientation to becoming material impetuses for approaching space, time, energy, and expression in attuned and responsive ways. In netherness, the 'unruly' (Nielsen 2016, para 8) associations of endometriosis with blood, menstruation, infertility, or incurability that naturally plunge those who suffer from it into the ill-defined or hidden netherworld of the 'abject' (Kristeva 1982) or grotesque, are honoured.

Such a recalibration is significant not only for endo sufferers and artists affected by endo, but also for advancing research on endometriosis. As such, this chapter represents some of the research's greatest contributions of knowledge. The richness of an endo identity and experience becomes visible, audible, and palpable through netherness — inspiring greater understanding, compassion, and empathy for those suffering from the disease. Privileging the sensory, somatic, and artistic, it generates revolutionary perspectives surrounding experiences associated with endo. Rooted in interdisciplinarity, it revitalises and produces inclusive language for the fields of performance and improvisation studies, painscape research, feminist theory, and disability or crip studies. Vitally, in

encompassing endo identities, voices, and bodies, netherness becomes a valuable tool for crippling an embodied creative practice and in its use, not only recovers ‘the cripistemology and politics of pain’ (Patsavas 2014: 205 as referenced in Chapter 1), yet expands it to specifically include and draw awareness to endometriosis and other female pain experiences.

The Strands of Netherness

This chapter discerns and scrutinises the three distinct strands of netherness which can be succinctly described as: inviting states of in-betweenness; embracing non-normative spatiality; and reorienting towards alternative temporalities, atmospheres, or energies. Each strand presents opportunities for transformative shifts and exhibits idiosyncratic characteristics that stem from embodying and embracing lived-body experiences of endo. When amalgamated, they jointly contribute to a comprehensive conceptual framework that, beyond serving as a unique articulation of endo experiences, can be harnessed to assist other creative practitioners or artistic researchers in generating endo-informed work. With the expansion and development of each strand’s endo-centricity, netherness supports the retrieval of ‘dismissed voices’ and addresses misrepresented and invisible experiences of gendered pain or disability (Garland-Thomson 2005: 1557 as referenced in Chapter 1 and 4 discussion around feminist crip research approaches).

I include some examples of how the various strands of netherness may be conceptually or aesthetically understood in *Nether Space(s)*; however, these are not definitive readings. Likewise, because of its reliance on improvisation and the diverse stories of different bodies, netherness materialises differently depending on how and by whom each strand is explored. Its open-ended nature allows for continual reinterpretation and adaptation, fostering an inclusive and dynamic framework for understanding and expressing endo experiences.

I. Navigating the Dichotomies of Endo: Inviting Liminality

First, the notion of *liminality* distinctly emerged as a defining characteristic of netherness. This strand originates in the theoretical and creative navigation of endo bodymind’s inherent ‘split self’ in connection with Nielsen’s discussion of dissonant disabilities (as mentioned in Chapter 1); Kafer’s concept of ‘embodied dualness’ (2013: 39 as referenced in Chapter 2 and 3); and Kupperts’s notion of the scar as a ‘meeting place between inside and outside’ (Kupperts 2007:1). This sense of in-betweenness, which manifested through both individual presence and conceptual intention, consistently weaves through the subsequent strands, serving as a metaphorical and unifying thread of inquiry.

As theoretically revealed in Chapter 2 and more experientially in Chapters 3-5, many individuals with endo experience a profound and bewildering concurrence of dualities or binaries. Though age, diagnosis, treatments, recovery periods, and life circumstances impact its ebbs and flows, at the very foundation of this intricate and often paradoxical narrative is the way endometriosis fundamentally splits our bodies and identities into two women: the woman in pain and the woman recalling/

anticipating pain. In this research for example, collaborator Mei expressed this as ‘broken woman’; I referred to my experience as a ‘split self’. Frequently, this ‘broken woman’ or ‘split self’ exists in a murky space of temporal, corporeal, and/or existential dissonance.

Endo sufferers and individuals with other ‘dissonant disabilities’ (Nielsen 2016 as mentioned in Chapter 1) often live in a nebulous terrain characterised by the intersection of chronic illness/pain and disability, producing simultaneous feelings of control and surrender; sickness and health; or ‘ability’ and ‘disability’. In endo, the discordant self’s liminal state is perpetuated by the unpredictable nature of endo-related experiences, which oscillate between periods of intense pain and symptom remission or management (as discussed in Chapter 1 and 2). This negotiation reflects a state of ‘embodied dualness’ (Kafer 2013: 38) and frequently provokes the integration of crip time, for example. Such an embodiment, where one’s relationship to time, space, body, and energy fluctuates based on endo-related experiences, invites a kind of ‘crip liminality’ (Kafer 2013: 38). It also calls for an improvisational presence that encourages a reverence for the unforeseen, spontaneity, and heightened awareness.

As is the case with endo, the ambiguity surrounding the trajectory of chronic pain — whether it will improve, worsen, or persist — leaves individuals in a state comparable to initiates during the liminal stage of initiation ceremonies (Turner 1967). However, the comparison extends beyond a mere transitional phase; these sufferers also resemble permanently liminal figures. The concept of liminality has been linked to individuals suffering from other chronic pain conditions (Jackson 2005). In analysing the stigmatisation experienced by chronic pain sufferers, renowned anthropologist Jean E. Jackson points to various features of chronic pain that produce an ontological status straddling several boundaries, leading to the perception of chronic pain sufferers as ‘liminal creatures’ (Jackson 2005: 332). In many ways, the status of chronic pain sufferers, including endo sufferers, eludes a definitive categorisation—they exist as ‘not-quite-either’ and ‘some of both’ (Jackson 2005: 345). Consequently, Turner’s distinction between the liminality associated with states that are ambiguously defined and that characterising ritualised transitions both hold true here.

Netherworlds often similarly signify in-between states or places of transition, such as limbo or purgatory, for example. Atmospherically, netherworlds and other liminal places are often perceived as haunting or eerie due to: a fearful association with the unknown; the overall destabilising nature of ambiguity; or the unsettling tension of existing between two states. In a nether practice honed in on liminality, contrasting selves simultaneously converge and diverge: unsteadily dancing in the betwixt and fluidly existing in the in-between. Improvising with various binaries allows for their revelation, leakage, and deconstruction, ultimately yielding a similarly powerful, tension-filled environment, mood, or presence. Here, we become scars ourselves.

As evidenced in this project, the cultivation and exploration of nether liminality manifests through two distinct avenues within an artistic practice: embodied liminality and conceptual liminality. In a creative journey of netherness, these pathways, while interrelated, maintain a degree of autonomy.

The former pertains to the individual body's capacity to harness and embody liminality, encompassing facets such as performative presence and artistic expression. The latter involves intentional considerations of various dualities that may exert influence beyond the individual body, shaping other elements within an artwork or painscape. In the realm of performance painscapes, these additional elements contributing to the nuanced realisation of netherness may encompass the sound-score, poetic/written components, overall format, spatial considerations, relational dynamics, costuming, and the colour palette. Collectively, netherness articulates the bodymind limbo inherent to endometriosis through the interactions of embodied and conceptual liminalities.

Individual arts practices can uniquely explore these methods, yet there are general areas of in-betweenness crucial to cultivating nether liminality. These more overarching dichotomous themes are related to core principles within a painscape/crip arts practice and are related to an endo-centric focus. For instance, the categories of self and other, visible and invisible, and public and private are crucial to the practice and realisation of netherness.

First, considering the dynamics and relationships between **self and other** is a key aspect, particularly in the creation of painscapes and endo-centric painscapes are no different. For the purposes of this project, the 'other' referred to other sufferers and non-suffering witnesses like peers, family members, or medical professionals. Generally speaking, an improvisational and feminist/crip methodological focus on co-creation and collaboration invites these kinds of unions, as illustrated in this research. In particular, expanding, erasing, or merging the boundaries between self and other invites a unique realisation of netherness in which the unknown and known or the real (narrative) and imagined (interpretation of narrative) co-mingle and co-exist. In *Nether Space(s)*, embodied details from my own lived reality fuse with the other women's bodies and voices; our pain intertwines and its echoes result in a hybridity marked by autobiography, storytelling, abstraction, emotion, and viscera. Our experiences, separate yet communal, come alive in poetry, abstract painting, movement vocabulary, and a dynamic avant-garde sound-score. Bridging our bodies and our stories, netherness activates a robust middle ground.

For instance, the poetic painscapes in *Nether Space(s)* might feel particularly representative of an in-between space of self and other. Likewise, the poetry's fluid manifestation across different disciplinary forms — written, spoken, and painted — demonstrates their deeper role in conveying a nether sense of dissonance. The origins and content of the final poems as well as their integration in the final production establish a liminal world not only of self and other, but also of abstract and literal; real and imaginary.

The original poetry spoken by collaborators as well as the audio recordings of medical practitioners punctuate the sound-score which features the compositions of composer Marcus Amaker. While the electronic music generally establishes an atmospheric backdrop, imparting a sombre mood that evokes intensity, disruption, and uncertainty, the poems seem to intensify the atmosphere. No matter how the performers' bodies are visually perceived by the audience, the poems substantiate the

brokenness of six bodies; communicating the unwanted darkneses, disruptions, and uncertainties of the disease. Endo's realities come to life through the voices of the collaborators which drip in raw emotion and anguish. Correspondingly, throughout the score, sporadic intervals of meditative silence or sudden bursts of emotional vocal repetition disrupt the conventional flow — perhaps drawing the focus of performers and audiences inward and outward, further establishing the poetry as a site of contradiction and uncharted land where boundaries rupture.

Generally-speaking, the whole of the (nether) practice, rooted in my expertise in improvisation and experiential performance, as well as my endo-centred autobiography, embodies a distinct practitioner-researcher knowledge (as outlined, for example, by performance studies scholar Susan Melrose) that intuitively informed my interactions with both collaborators and audiences. Years of navigating boundaries and thresholds in both performance-making and lived experiences of endometriosis have cultivated a nuanced, dynamic approach to relationality within the artistic research and the acts of performance. This 'expert or professional, discipline specific intuition' (Melrose 2006: 99) and embodied knowledge enables a sensitivity to the ways in which personal and collective experiences of pain can be respectfully shared, understood, and interpreted, guiding each interaction with an awareness of both proximity and separation that is integral to the practice.

Specifically, a conceptual boundary akin to a scar or 'membrane' emerges as a defining aspect of this practice, shaping the ways in which pain is communicated, witnessed, and interpreted by both audiences and collaborators. This boundary embodies both proximity and distance, capturing the dynamics of engaging with the lived experience of pain while acknowledging the inherent separation that exists in witnessing another's suffering. In various performance contexts, this scar-like boundary allows for moments of closeness, bringing audiences into intimate proximity with my body and pain narrative, yet always preserving a layer of separation — a reminder that pain, especially chronic pain, might resist full empathy or comprehension. This separation mirrors the complexities and partial incommunicability of pain, where complete access remains elusive. As a framework within performance studies, this boundary becomes a tool for navigating the nuanced space between performer and audience, allowing for a delicate balance between intimacy and detachment.

For audiences, this membrane boundary serves as a productive site of exploration that mediates their engagement with pain. It highlights the limits of empathy and traditional spectatorship, as audiences may experience glimpses of embodied connection without fully crossing into the performer's experience. By interacting with and at its edges, spectators are encouraged to move beyond passive observation, instead confronting their own limitations in perceiving pain. Occasionally, the 'membrane' may be 'punctured' through specific performative choices — such as outward eye contact, shifts in spatial dynamics or intentional disruptions of conventional spectatorship — that invite the audience to transition from detached observation to a more embodied and empathetic response.

For different audiences, this boundary is adjusted to reflect the varying dynamics of gaze and engagement. For instance, when performing for a medical audience, the scar-like membrane may serve as a protective layer that resists the clinical gaze, limiting opportunities for rupture to avoid reducing the experience of pain to mere observation. In contrast, when vulnerability is central to the interaction, as with general audiences more open to empathic engagement, the performer might invite moments that traverse this boundary explicitly, creating disruptions that challenge the audience's perception and encourage a more visceral, embodied response. This framework respects the distinctness of the performer's experience while fostering layered, reflexive engagement, allowing audiences to connect with pain's complexities without presuming full understanding.

A similar scar-like boundary arises within my collaborations, marking both the shared and individual aspects of the practitioner-researcher relationship. This boundary creates a selective, porous space that balances individual agency and shared vision, shaping each collaborator's involvement without collapsing our distinct perspectives. Through decisions around representation and authorship, we navigate issues of ownership and visibility, engaging in a collaborative space that allows contributions without assuming a singular voice. The scar metaphor reflects this process, where our exchanges are shaped by both openness and boundaries, inviting collaborators to engage with my lived experience of pain while preserving their unique interpretive roles. This practice fosters a space where shared insights into chronic pain can emerge, yet without attempting to fully conflate our perspectives.

These scar-like boundaries ultimately define the edges of this practice by clarifying what it does not seek to achieve. The work does not strive for complete transparency, nor does it presume to fully articulate the pain narratives of others; rather, it interprets and shares glimpses of embodied pain while respecting the individuality of each collaborator and performer. Likewise, it does not force audiences into the role of empathetic witness; instead, it offers moments of resonance and layered connection, fostering a shared experience that honours pain's complexity. Through these adaptable boundaries, the practice contributes to performance studies by modelling an innovative approach to audience engagement and collaboration in the context of chronic pain. This nether approach to self and other, grounded in practitioner-researcher expertise, bridges personal experience and shared understanding in ways that both intuitively and consciously respect the inherent challenges of representing pain.

Next, blurring and traversing other boundaries, like those between **visibility and invisibility**, constitutes a significant avenue toward embracing a nether state of in-betweenness. Given the physical invisibility of endometriosis and its role in the marginalisation, trivialisation, or stigmatisation of female pain, it becomes imperative to explore how both the hidden interiorities and experiences of endo might be externalised or represented through alternative means. Beyond the more obvious attempts to externalise and interpret pain and other hidden aspects of endo bodyminds, scars emerged as pivotal liminal sites, deeply contemplated for their symbolic and medical significance. Acting as both sites of production and threshold zones, scars tangibly signify a refusal to anchor in a

knowable reality or stable truth (Kuppers 2007: 153). This liminal quality is particularly evident in the physical imprints many endometriosis sufferers bear, which serve as unique forms of self-expression and testaments to their lived experiences, marking the transition between internal suffering and external visibility.

Throughout the research and in *Nether Space(s)*, not only was poetic language woven around scar imagery and narratives, but also the encouragement of visualising and touching scars, whether on my body or the collaborators', became catalysts for gestural vocabulary, improvisations, and thematic movement rituals (yarn wrapping or unwrapping). As mentioned in Chapter 5, this intuitive imagining yielded what one audience member referred to as a 'suturing' gesture among other related motifs. Additionally, by leveraging the insight offered by scars as sites marking embodied histories, the kinaesthetic paintings could be perceived as artefacts representing both the act of live performance and the expression of pain, laying bare the intricacies and complexities of pain, trauma, and healing. In an endeavour to articulate the unseen and unheard stories of six endo warriors, many of the artistic layers of *Nether Space(s)* authentically claim a space between concealment and revelation.

Notably, the in/visibility of time through the lens of trauma is also a consideration in this sub-category of liminality. For instance, scars not only confound borders of visible and invisible, they implicitly signal the passage of time. Scars bridge the past with the present/future, tracing memories of pain. Throughout the research process, both the collaborators and I consistently recognised that, even during pain-free moments, individuals with endometriosis possess the ability to vividly imagine and viscerally recall pain, transcending mere memory recollection. In this sense, endo pain creates a corporeal residue reminiscent of trauma, haunting the body and persisting even in the apparent absence of acute symptoms. When experimenting with scars as representations of the 'ghostly matters' of ill-defined diseases (Overend 2014:63) such as endometriosis, a practice or aesthetic of netherness might be imbued with a sense of hauntedness.

In the case of *Nether Space(s)*, the musical sections enlivening the overall score might convey this kind of eerie tone. The experimental music, characterised by its intensity, with dark, low-frequency pitches, seems to create an atmosphere of unease. The use of dissonant harmonies, sustained bass notes, and slow tempos potentially contributes to a haunting soundscape. Techniques such as reverb and echo effects likely enhance the spectral quality, while the incorporation of atonal melodies and sparse, minimalist textures could be perceived as mirroring the unsettling and tumultuous experiences of endometriosis. This auditory backdrop, rich with ominous drones and resonant, brooding tones, appears to deepen the sense of hauntedness and underscore the themes of pain and disruption central to the performance. Similarly, the bodysuits might also deeply align with the scar as a marking of historical pain. Transformed through the act of pain expression and articulation in the painting solos, they might serve as tangible representations linked to the pain's perpetuity and endurance as trauma or residue.

Finally, the exploration of liminality, specifically navigating the space between **private and public** realms, results in the transforming of the **personal into the political** and vice versa. This in-between space, where conventional hierarchies between audience and performer are problematised, serves as a conduit for public education, community building, and advocacy — common objectives underlying the painscape practice. These explorations become particularly poignant when addressing medical gaze and considering the role of medical spectators in shaping female pain narratives. Deconstructing or unsettling the boundaries between private and public (and/or medical) domains has implications for determining elements such as performance site or format, as well as shaping the dynamics among performers, artwork, site, and audience.

For example, in *Nether Space(s)*, as revealed in Chapter 5, the museum rotunda context and its theatre-in-the-round arrangement suggest a deliberate blurring of conventional boundaries between the performer and the spectator, or distinctions between the public and private realms. The audience's proximity potentially increases tension and might prompt questions about whose body is being presented. Who assumes the role of witness or the witnessed? The presence of contemporary, abstract paintings, juxtaposed within the traditionally conservative museum space, marks the territory as contested ground. A palpable friction seems to arise from the contrast between the personal declarations of openness and revelation in the artworks and the historical formality and patriarchal systems associated with the space.

Relatedly, the development of the 'Mei' painted painscape in a medical education setting delineates a nuanced exploration of liminality where my roles as artist, educator, and patient converged. In this instance, the traditional boundaries of the medical sphere are challenged through the deliberate invitation of fluid slippages between the roles of witness and the witnessed. This embodied intersection, coupled with the contextual backdrop, seemed to elicit a collective journey into a liminal borderland where the personal, public, and medical domains coalesce.

Moving beyond conventional narrative medicine structures, live performance serves as a potent vehicle for authentically revealing deeply personal and non-sterile versions of navigating endometriosis. This process, characterised by substituting medicalised language with embodied expression, restores agency to those experiencing pain and to the body itself. It also establishes a genuine channel for knowledge exchange, fostering compassion and empathy. The profound implications of nurturing a public/private space are appreciably explored in the forthcoming research considerations within the Conclusion chapter.

As in this research, a proactive exploration of netherness is conducted through dual creative channels of embodied and conceptual inquiries into liminality. Such an approach warrants a nuanced understanding of endometriosis's split self embodiment, as evidenced in the distilled elements comprising *Nether Space(s)*. Furthermore, a creative expedition into the netherworld of endometriosis reveals a mood and tone that are not only tense, unsettling, and disorienting, but also politically charged, portraying a complex interchange of bodily and societal experiences. Within this exploration,

the scar, a ‘bodily border situation’ (Kuppers 2007: 196), can be incorporated as a potent symbol, positioned in a liminal space between the self and the other; the visible and the invisible; and the then and now.

II. Embodying Pain & Disruption: Resisting Uprightness/Inviting Alternative Locomotions

Next, netherness can be explored and uncovered through nuanced embodiments of endo pain (migraine, cramps, low back pain, pelvic pain) and other disruptive experiences associated with the disease (surgery, recovery, infertility treatments). In this research, specific trajectories, locomotions, and positions, characterised by liminality, lowness, or non-verticality/horizontality, have been revealed as endo-informed embodiments as pain forces the body into downward trajectories as well as lower spatial environments. As described or demonstrated by collaborators and as experienced in my own physicality, endo bodies are often caught in a physical kind of limbo attempting to find relief and alleviate pain. Our bodies struggle between hoping and desiring to be or remain vertical, while being pulled downward by an uncontrollable force (pain). The lowering to the ground and the body’s refusal of verticality happens as a natural result of the localised pain in the pelvis and lower back. Frequently, endo bodies might require support from the floor or other structures in the space (a toilet, a bed, a chair).

Since the term ‘nether’ itself is defined as lower-level and indicates downward movement towards the ground or the underground, an endo body’s spatial relationship to netherness is indisputable. Such spatial attributes, summarised as *a resistance of uprightiness*, or indeed, *a celebration of downwardness and/or the grotesque-ish*, prompt a discussion centred on physicality, movement expression, and relationality within the realm of performance. These specific attributes speak to the underlying liminality of netherness and add specificity to its articulation of endometriosis experiences.

Embodied nether tendencies were clearly evidenced in and through all the creative pathways described in Chapters 3, 4 and 5. In particular, an analysis of the creative explorations and input from collaborators across Phase I and II of the research exposes non-vertical/grounded bodies, bodies doubled over, bodies in foetal postures, or bodies in bracing positions as repeated endo-centric embodiments. In the Phase III creation of *Nether Space(s)*, netherness and a marked resistance to be completely upright, dictated the structure and conception of improvisation, as well as the overall development of the choreography. Towards the conclusion, the research adopted an affirmative stance towards these resistances and diverse abilities, recognising them not only as expressions of pain, but also as somatic attunement. As alternative, non-vertical, and in-between postures and body language were increasingly embraced, the research demonstrated a decisive allegiance to spatial and corporeal netherness. Through this strand, pain and disease are conceptually repurposed, influencing the overall aesthetic and movement material.

As alluded to throughout, horizontality emerged both conceptually and aesthetically as a prominent creative orientation within this research, which will be further explored in relation to nether energies below. However, one of the most compelling nether spatialities observed involved the body adopting a ‘doubled over’ or ‘hunched over’ posture (first mentioned in Chapter 3 referencing dance artist Emilyn Claid’s rumination on slumping or stooping as bodily stages of falling). This non-vertical position, paralleling a monstrous hunchback, was recurrently embodied by both myself and other individuals with endo and asserted in reflective writing, dancing, and collaborative exchanges. This bodily positioning appears to express a spectrum of endometriosis-related disruptions, including low back pain, pelvic pain, uterine cramping, mental defeat, shame, or total depletion. The body’s centre struggles to support the weight of the torso, and being stooped over or in proximity to horizontality provides at least minimal relief.

When experiencing symptoms of endometriosis, my own pain-induced transformation from upright, poised, athletic, professional dancer to awkwardly hobbling, inelegant, out-of-body, stooped creature is dramatic and abrupt. Moving in and out of this estranged physicality, a different embodiment from my customary able-bodiedness, the invisible seems to become visible. Through intentional improvisational movement explorations, which then become distilled into a vocabulary, the inner grotesqueness of disease or pain may find ways to be partially unveiled. Purposefully improvising with hunchback posturing and the body’s negotiations with internal and external space, the distortions and contortions that are so readily felt internally are finally seen — an empowering act in and of itself. The inner grotesque disease, the monster living within, discovers a way to be external and present outside of the self, even if allowing only a glimpse of its violence. Endo’s status as an invisible disability and bodily difference cloaks feelings of abnormality, deformity, or monstrosity that those of us who suffer might experience towards our own bodies. Engaging with netherness disrupts this status.

Relatedly, metaphorical associations and sociocultural implications of endometriosis’s grounded embodiments and downward body trajectories suggest a connection between netherness and the monstrous feminine, grotesque, or abject. This manifested not only in interpretations of the artwork, but also, in the language of collaborators: ‘ugliness’ (Toby, February 2022); ‘big monster’ (Mei, May 2022); ‘zombie’ (Danielle, May 2022); ‘hunchback’, ‘slightly scary’, or ‘monstrous’ (Kate, February 2021). Through this connection, we can engage with netherness through the established feminist positioning of the research, analysing how cultural representations reflect and reinforce patriarchal anxieties surrounding women’s bodies and sexuality.

For example, Julia Kristeva’s theory of the abject refers to that which is expelled from the body or from social order, evoking feelings of disgust or horror. The grotesque, as a literary and artistic device, involves combining contradictory or incongruous elements to create a sense of distortion and disruption. Additionally, Barbara Creed’s monstrous feminine (1993) is often depicted in grotesque forms that exaggerate and distort the female body, emphasising its otherness and threatening nature.

Representations of the monstrous feminine frequently portray the female body in grotesque forms, unsettling conventional notions of beauty and femininity. Similarly, the monstrous feminine often embodies aspects of the abject, such as bodily fluids, decay, and excess, which challenge notions of cleanliness and purity associated with idealised femininity.

In the context of corporeal netherness, the concepts of the grotesque, abject, and monstrous feminine demonstrate how endo bodyminds challenge traditional notions of femininity and bodily integrity. By exposing the messy and painful realities of female embodiment, netherness departs from gendered ideals of bodily perfection and control (Butler 1990), which relegate women to passive objects of male desire (Irigaray 1985). These embodied explorations, drawing from stigmatised experiences of the abject, support a reevaluation of what it means to inhabit a female body beyond patriarchal constructs of beauty and normalcy. Connecting netherness to this feminist thinking underscores its radical potential as a site of resistance and transformation.

The grotesqueness and monstrosity externalised in the lower positionings, and in netherness more generally, at least partially originate in what verticality and non-verticality represent in Western culture. In the context of dance especially, verticality and an upright balance signifies ‘linear harmony’ and ability to achieve strong poise (Claid 2013: 74). Poise is often interpreted in Western contexts as a body’s readiness for mobility and graceful state of upwardness in posture and presence. A poised body carries a sense of stability and equilibrium which can be read as confidence and sure-footedness. These characteristics of poise and verticality have been heavily emphasised in ballet and are associated with an Apollian sense of beauty, for example (Claid 2013). Claid who has demonstrated interest in disentangling the physical and metaphorical act of falling (first mentioned in Chapter 3), reflects on her early training in ballet in terms of verticality:

Be better, be higher, be upwardly bound, be thin, be long-necked and straight-backed – or be shamed. Although dropping is integrated into ballet technique and language (*plié*, *tombé*) these are usually preparations for upward movements, to support the aesthetic of transcendent linearity. (Claid 2013:78)

Her feelings reveal ingrained traditions of beauty and superiority especially in the field of dance, but also universally, for (Western) aesthetic ideals in body language. In some cases, being upward and vertical is inadequate. In particular, women are expected to transcend normal upwardness with the use of pointe shoes in dance contexts or high heels in everyday life contexts. The higher the body, the better the body; a woman in pointe shoes or high heels stretches beyond traditional verticality towards unattainable, transcendent heights. Indeed, a vertical body or the more upright body tends to assume some level of power over a physically lower body. Likewise, (Western) definitions of prosperity and achievement are often culturally framed along an upward curve so that ‘downward mobility becomes exclusively associated with shame...every fall from the ladder becomes a fall from grace’ (King 2004: 35). The sociocultural tendency towards upwardness is akin to a tendency towards perfection and able-bodiedness: ‘Physically slumping symbolises a lower status, provokes shame, loss of dignity,

inferiority and failure' (Claid 2013: 78). Additionally, bodies paused in horizontal or foetal positions, can conjure feelings of devastation, failure and inferiority (Albright 2018).

In embracing the vantage point afforded by netherness, one might reject a hasty return to the realm of uprightness and idealised constructions of femininity. Rather, we might cultivate an environment where creative insights are nourished and invigorated by our own physical disruptions. Deliberately and purposefully engaging in either partial or full descending motions, the body is participating in and representing the experience of lowering to positions re-conceived as resistance, rest, recovery, and repair (Albright 2018; Sharrocks 2013). In this trajectory, staying low, indeed, inhabiting nether spaces, presents opportunities for self-preservation and healing as well as the facilitation of new expressive vocabulary (Albright 2018, 2019). Indeed, being grounded and dwelling with endo-initiated disorientation might offer a place of rich self-discovery and transformation: 'Horizontalizing people offers a different viewpoint – rest, recuperate, recover, reflect – suddenly you become aware of how much effort it takes to stay upright, to carry on ... going on' (Sharrocks 2013: 52).

Improvising and creating with horizontality and 'monstrous' or grotesque-ish postures challenges the conventional quest narrative and, in doing so, offers a distinct path which embraces crip futurity and resilience. This path celebrates the normality of different bodies and female bodies 'doing things differently' (Hansen and Philo 2007: 493). To intentionally champion the horizontal body, the downward body, or the slumping body wavering between vertical and horizontal, is to accept our own imperfections, our fallible humanity, and importantly, our resilience. Indeed, explorations of falling, stooping, slumping, or groundwork in a performance and movement practice exposes the 'precariousness of life' and offers an opportunity to 'rejoice in a freedom from uprightness' without the shackles of shame (Sharrocks 2013: 48, 52). In this sense, the performative incarnations and natural embodiments of endometriosis coalesce. This union opens up possibilities for expressing the unseen and unheard aspects of disease or pain, as well as rediscovering the potential for embodied agency.

In summary, in a nether performance or movement praxis, embodied expressions originating from the experience of pain and the complexities of endometriosis become an integral part of shaping novel body vocabularies. Pain influences the exploration of different bodily arrangements, suggesting that netherness emerges not only as a response to pain, but also as a means of creatively engaging with the body in space and the body's spaces. Tapping into the improvisational strategies particularly around somatic consciousness and adaptability might welcome engagements that are perhaps not merely alleviations of pain, but 'pleasurable' or as 'playful as they are serious' (Kuppers 2008: 77-78).

III. Reorienting towards 'Elsewhere' & 'Otherwise'

Finally, rather than evading the more adverse connotations of endometriosis, netherness invites alternative modes of being, sensing, and creating. This reflects a curiosity in representing what Frank denotes as a 'chaos' narrative (1995, refer to Chapter 1) or what Kafer refers to as crip futurity (2013).

By calling upon the practices of care implemented by endo bodyminds as a result of pain and interruption, like crip time, netherness encourages artists and audiences to *reorient towards energies, temporalities, and atmospheres of 'elsewhere' and 'otherwise'* (Kafer 2013: 23-24). Particularly, this strand presents alternative temporal or energetic manifestations of netherness like stillness, deceleration, repetition, and non-linearity.

As proffered in the thesis introduction, netherworlds evoke images of underworlds, limbo, or subterranean spaces, connoting darkness, subversion, and dissidence. This strand appropriates and reinterprets these connotations by examining the 'dissident' qualities inherent in endometriosis and other 'dissonant disabilities' (Nielsen 2016). This section delves into creative modalities that acknowledge loss, appreciate subversion and disharmony, and remain receptive to the non-traditional and authentic, avoiding 'normalising impulses' (Kafer 2013: 23). The strategies in this strand and the resulting aesthetic further showcase netherness as a conduit for 'resistant orientations', enhancing its role as a 'strategy of dissent' (Kafer 2013: 15, 40). Thus, the ostensibly dark netherworld of endo transforms into an illuminating space where distinct energy choices transfigure pain into resilience. Resisting the 'regimes of the normal' (Patsavas 2014) contributes to fostering a 'desire for what disability disrupts' (Kafer 2013) and a reorientation towards the 'elsewhere', 'elsewhen' and 'otherwise' first referred to in Chapter 2 (Kafer 2013: 24).

In conjunction with the visceral sense of uneasiness and discomfort conveyed in pain's spatial nuances, improvisation invites an immersion and embodiment of 'strange temporalities' like crip time and crip futurity (Kafer 2013: 35). These coalitional endeavours give rise to what Hopfinger terms 'a certain quality of moving' (2021:128), characterised by distinct energy shifts. In this project, reorienting towards a nether elsewhere or elsewhen unfolded through variances in pace, rhythm, mood, or flow, stemming from synchronous embodiments of pain and care/relief. Such an energetic reorientation introduces layers of significance into both individual and collective endo narratives, where pain ceases to be an abyss of despair, and vulnerability is liberated from the constraints of societal perceptions of weakness.

First, this strand of netherness can be invited into a practice through various alternative temporal or energetic explorations in movement and musicality. Deliberate deceleration; intermittent or chaotic bursts of intensity; and cultivation of stillness play critical roles in both honouring pain and championing repair, rest, or recovery for the body. For instance, in a more conventional movement practice when compelled to transition to a more horizontally supported posture, the initiation of floor work may manifest initially with unhesitating spontaneity and a liberated sense of abandon. However, endo experiences of menstrual cramping, profound fatigue, or migraine disrupt this mode of movement engagement, compelling an individual to decelerate or seek states of stillness as a responsive strategy. The creative honouring of such interruptions must therefore include this dynamic of slowness and stillness representing both the demands of pain and the necessity of crip resilience as a form of care. Generally, the movement expressions incorporate these compulsions as: slow and

gentle moments as bodies transition in and through endo-centric postures of pain; extended pauses; or slower paces as performers breathe and rest.

When enacting embodiments of disease or trauma or contending with symptomatic expressions of endometriosis, the predilection for a subdued energy level or requisite repose/crip time can evoke a pervasive sense of defeat. Generally, the experience of stillness or slowness, particularly when dictated by external factors like pain rather than volitional choice, be it within the domain of movement expression or other situational contexts, often lacks the perceived attributes of productivity or restfulness. The obligation to endure or iterate various adapted bodily configurations, gestures, rhythms, or tempo may precipitate a sense of powerlessness or result in external perceptions of fragility. Specifically within the context of dance or performance art, observers frequently harbour assumptions that the body will effortlessly ascend and energetically revert to a vertical orientation (Albright 2018).

Working authentically with such shifts, feelings of stagnation or sensations of ‘stuckness’ are also embodied. Sensations of stuckness, powerlessness, or defeat resonate with the reality described by feminist writer Ann Cvetkovich, whose work I considered at this reflective point of the research. Cvetkovich characterises stuckness as an impasse inherent to certain diseases, like depression, which she notes often arises from ‘a failure of societal imagination’ (2012: 20). Analogous to Baraitser’s theorising around maternal interruption (Chapter 2), Cvetkovich goes on to indicate that in navigating experiences of being or feeling stuck, responses that emerge may serve to invigorate imaginings not conventionally accessible. These responses can become innovative ways of living and at times, manifest as a transformed sense of body or insight into new ways of moving.

Similar to Cvetkovich’s theoretical term ‘ordinary habit’ which was elicited by an analysis of art, culture, and media, engaging with netherness as a creative response to stuckness, and indeed interruption, ‘creates space and tolerance for being stuck, treating such experiences as worthy of exploration’ (2012: 21). While endometriosis remains incurable, the prospect of working through its many and repetitive forms of impasse lies in ‘embracing flexibility or creativity’ as suggested by Cvetkovich and this research’s methodological framework and in discovering ‘movement that manoeuvres the mind inside and around [the] impasse’ even if that movement seems backward or resembles retreat (Cvetkovich 2012: 21).

As an example, in the ‘She’s Fine’ section of *Nether Space(s)*, the trio of dancers hold their bodies in slumped positions, slowly moving in an intricate spatial pattern. The movement’s pace provides dancers with an opportunity to catch their breath and recuperate from the dynamic movement bursts of the preceding improvisations. While not inherently technically challenging per se, this segment demands significant concentration and presence. If the body does not fully relax into the phrase work, it can lead to tension and soreness in the low back muscles. In essence, the choreography necessitates a mindful, recuperative approach for its optimal execution as well as its aesthetic realisation. In another section, the performers fall to the floor following a burst of choreography. They are

encouraged to lie in supine or prone postures for an open-ended extended period of time, ‘stuck’ in a moment of repair. Their unmoving bodies might be perceived as lifeless, catatonic, or expired; yet read through a crip lens of netherness, they are in fact, harnessing energy in order to rejuvenate and reset. Instead of moving independently when they rise, the performers support one another in slowly ascending from the ground.

Relatedly, gestural expression, unsettled repetitions or rhythms where bodies ebb and flow in disorientation and restlessness, and the utilisation of support (like the ground or other bodies) might also be prioritised over more ‘virtuosic’ expression. Expanding from the nuanced non-vertical spatialities and trajectories, a netherness practice and/or aesthetic might also engage in ‘pedestrian’ positions for extended durations or focus on intricate gesturing with the less endo-impacted body parts like hands, fingers, toes, shoulders, or arms. In general, a more inward-directed focus at times, might perhaps be evoked by actions of ‘dwelling’ (Albright 2018 mentioned in Chapter 3) on memories of pain, either accompanying or instigating these creative choices. The lens of netherness strategically reframes gesture, repetition, support/stillness, or other moments that might be perceived as mundane by an audience, presenting them as opportunities to enlighten the audience about the particular requirements of recovery and healing for an endometriosis-afflicted body. Hopfinger articulates my own sentiment eloquently when she writes:

When my movements emerged from a place of care I was able to let those movements take their own time and to ‘let go’ of my expectations about what makes a choreography interesting. From my professional experiences and training in contemporary performance, I think that I have developed (and internalised) certain ableist expectations of what makes choreography interesting, such as: avoiding gestural movements that overly use the arms and hands, where arm gesture is considered too simplistic and not embodied enough; and, that embodiment is most ‘authentically’ expressed through fully ‘giving in’ to the body where we allow our bodies to – often in a physically demanding way – enact wild and vigorous movements, where movement is understood to ‘take over’ the body (2021:128).

Furthermore, another avenue for exploring this reorientation involves experimenting with and realising non-linearity, dissonance, and disorder in the expression of lived-body experiences. As discussed in Chapter 1, prevailing narrative structures in illness storytelling often avoid anti-narratives that reflect chaotic experiences, revealing society’s inherent and ingrained preference for order and settlement. Departing from heroic ableist narratives that typically emphasise curative futurity and triumph over disability or disease, the overarching configuration of netherness discards any climactic arc or conventional conflict resolution. Instead, netherness practices and performances fully immerse themselves in the turmoil and darkness of endometriosis, punctuated by only fleeting pauses for relief, hope, and resolution. This immersion instils a pervasive sense of uneasiness for both the audience and the performer. In the realm of dance and performance, these creative elements may be considered subversive due to their departure from the conventional exhibition of fluidity or linearity. Within the

crip realm of netherness, they could be seen as informative, authentic, and insightful alternatives in response to the disruptive nature of pain.

Significantly, the inclusion of improvisation in the practice and performance of netherness becomes instrumental in shifting towards a more anti-narrative structure. By embracing spontaneity and unpredictability, improvisation not only invites the heightened awareness needed for practices of care, but aligns with the dissonant and non-linear nature of netherness, resisting traditional narrative expectations. As discussed in depth throughout this thesis, improvisation further empowers performers to respond authentically to the present moment, disrupting the conventional storytelling trajectory.

Moreover, echoing the approach observed in *Nether Space(s)*, the deviant and anti-narrative tendencies of netherness might be more readily perceived and manifested by considering site-specific and alternative settings or formats, fostering interactions between the audience and artists or artwork. Opting for unconventional venues challenges preconceived notions, creating an environment that prompts the audience to question and reassess assumptions about art and performance. Non-traditional settings allow for the contextualisation of physical and mental endurance or resilience within diverse environments. By situating performances in spaces not conventionally associated with strength, the concept becomes detached from physicality, offering opportunities for alternative expressions. This empowers performers to redefine and embody both power and vulnerability on their own terms. Additionally, the incorporation of diverse formats might facilitate exchange with communities less likely to frequent traditional performing arts venues. This inclusive outreach and creative engagement fosters a diverse audience, which is of course paramount for challenging stereotypes and promoting a more inclusive appreciation and celebration of difference.

Similarly, alternative settings enhance the connection between performers and the audience, often providing an intimate space for a direct and personal encounter with the embodied aspects of netherness. The proximity amplifies the impact of nuanced movements, expressions, and gestures, enabling the audience to discern the subtleties of the experience through an empathetic witnessing lens. In these instances, unrelenting eye contact or the tension and release seen between muscles and skin from small gestural actions can reveal courage, vulnerability, intensity, and passion. Perhaps, moving slowly or repetitively from one recuperative posture to another, especially up close, invites both the audience and performer to co-behold a creative metamorphosis with deepened presence and attention. Within the framework of a crip performance practice, the artist supports the audience's attunement to 'the small shifts of pain breath, or fluttering fingers, or a furrow building between the eyes' irrespective of their personal experiences with chronic pain or disease (Kuppers 2006: para 30).

The shifts introduced in this strand redefine entrenched perceptions of beauty, strength, and 'wholeness'. Rather than sustained dynamism, linearity, and flow, the qualities associated with netherness reflect an energetic wisdom pertinent to endometriosis recuperation. They validate alternative crippled conceptions of resilience, particularly within the realms of pain and disability. In

both life and art, resilience traditionally centres around the capacity to operate, create, and move as if unaffected by illness, disability, or pain. Yet, within netherness, as in other crip art practices, resilience is demonstrated differently and embodied distinctly in its responsiveness to the needs, realities, stories, and bodies of individuals with endometriosis (Hopfinger 2021). A nether energy arises from embracing the inherent limitations and possibilities of the body in its current state, turning movement or performance into a dynamic dialogue with the ever-evolving realities of endo. As such, netherness necessitates contemplating what bodies can safely do, focusing on the body's truth rather than adhering to ableist or patriarchal expectations. While my body's adhesions, lesions, scar tissue, damaged organs, and other pain residue may remain unseen, they are palpable through various expressions of energy.

Conclusion: Netherness as Lens

In this research, painscapes serve as both a methodological tool and a framework for exploring how pain is experienced, communicated, studied, and expressed (as defined in my conceptualisation of painscapes in Chapter 1). Drawing on the work of Gonzalez-Polledo and Tarr, painscapes facilitate the examination of the multi-sensory and non-verbal dimensions of endometriosis pain, offering alternative means to articulate and navigate its complexities without prioritising therapeutic or curative outcomes. This approach allows pain to be investigated not solely as a symptom but as an embodied experience that encompasses spatial, relational, and sensory dimensions, revealing how pain manifests beyond traditional clinical or verbal articulations.

By leveraging and expanding the niche realm of painscapes into methodology, the concept of netherness emerged as a distinct aesthetic and theoretical framework. Thus, netherness is both an outgrowth of and a complement to painscapes, embodying the knowledge generated through painscape methodology while advancing feminist, disability, and pain discourses and practices. While painscapes serve as the original methodological pathway for exploring pain's spatial, sensory, and relational aspects, netherness emerged by specifically focusing on the unique lived experiences of endometriosis. This distinction is critical: painscapes facilitate a general exploration of pain, whereas netherness hones in on the idiosyncrasies of endometriosis, addressing how these particular experiences are communicated, studied, and expressed. Netherness thus becomes a creative realisation of the foundational insights of a painscape research practice, representing a more targeted investigation into the nuances of endometriosis pain (as outlined in the above discussion on its three characteristic strands).

Through this research, the integration of painscapes and netherness not only enhances understanding of female pain and chronic pain but also contributes to art-making practices that centre pain as a transformative site of embodied knowledge and creative agency. This approach positions pain as a generative force, challenging conventional boundaries of suffering and agency in art and scholarship alike. For example, some of endo's most 'undesirable' characteristics — invisibility, uncertainty, ambiguity, instability, discomfort — are bound up in the original meanings of nether regions or

netherworlds. But rather than viewed as unilaterally unfavourable, netherness reconfigures them as evocative, meaningful, and generative. The cyclical and unpredictable symptomatology rendering the sufferer into split selves and the interior grotesqueness of a visibly ‘normal’, ‘female’, or ‘able’ body imbued with adhesions, lesions, cysts, and scar tissue are embraced as provocative sites of limbo. The endo body’s resulting precarious or unstable occupation of lower positions are celebrated as valued wisdom. Likewise, endometriosis’s connection to female nether regions or chronic pain invites contemplation around diversity and identity.

Netherness surpasses the mere representation of endo bodyminds — though this is essential for social justice and health equity efforts. As demonstrated in this chapter, netherness cripps endo pain as knowledge and material inspiration. In the process of crippling endometriosis, netherness becomes a source for embodied agency and transformation. Additionally, in its articulation of the unseen, unheard, and dismissed, it opens space for personal validation and empowerment.

Enacted as a creative pathway, it serves as a valuable compass for shaping artistic processes; fostering inclusivity within the arts; and advancing feminist, pain, and disability discourses by centring the experiences of those with gendered disabilities like endometriosis. In the realm of medical humanities and/or narrative medicine, it acts as a nuanced roadmap providing fresh rhetoric, embodied knowledge, and non-traditional expressions to enhance dialogues and cultivate understanding around women’s health concerns. Its attunement to chronic pain, menstruation, and in/fertility is especially useful.

Beyond its contributions to revolutionising these domains, netherness can be applied, with sensitivity and awareness, as a specialised lens. While other fields may offer broad perspectives for examining feminist disability and challenging ableist or gender norms, netherness uniquely captures intricate intersections, connections, and embodiments not often acknowledged or linked. With its refined interpretive scope, netherness specialises in rethinking and presenting subjectivities and identities in a granular manner. Its nuances and idiosyncrasies, reflective of endo’s own complexities, confer a more layered understanding of disability, gender identity, and pain, aligning with the ongoing project in disability studies and feminist theory to generate diverse perspectives and counter historical reductions of female or crip identities. The conclusion of this thesis will offer potential avenues, beyond a crip performance practice or painscape arts practice, in which netherness might be productively applied.

CONCLUSION: JOURNEYING INTO AND OUT OF NETHERNESS

My Pain, Her Pain, Our Pain

I.

Closed my eyes

Opened my arms

Bared my souls:

The woman in pain

The woman remembering pain.

Do you feel your dark blood

Pumping?

This project was born from my pain. Monthly disabling pelvic and back pain; burns from heating pads on the abdomen; years of untreatable migraines; one decade of suffering prior to diagnosis; seven surgeries and recoveries; multiple organ removals; four rounds of IVF; visible and invisible scars; litres and litres of red, black, and brown blood; innumerable flare ups and ER visits.

I embarked on this journey driven by an intimate, raw desire to transform my personal suffering and initiate ripples of meaningful change for others as well. Guided by my body's stories, the overarching research objective naturally surfaced: to explore various means of expressing experiences as ineffable as pain and as enigmatic as endometriosis. Galvanised by history's extensive disregard for women's pain and the specific disregard of medical practitioners' for my pain, the conjuncted aim and hope was to produce new knowledge and novel articulations in order to bring visibility and palpable resonance to the often obscured, marginalised, and silenced narratives surrounding female suffering and in particular, endometriosis.

As this research journey concludes, I reflect back to each exploratory work produced or each process experimented with over the course of this project. I repeatedly listen to the dialogues; I re-engage with the emails and texts from the collaborators; and I recall the pain stories heard from others who have not been a part of this project including those of my family and ancestors. Finally, I reconsider all the moments and ways in which endometriosis has disrupted my life. The collective pain and trauma fuelled and continues to feed my creativity.

Charting the Journey

At the outset, investigation was broadened through a comprehensive exploration of existing pain scholarship and engagement with theoretical inquiries concerning the transformative potential of pain communication. As the research progressed, after the consideration of a myriad of avenues (and shortcomings) around pain expression and illness narrative, the area of painscapes was honed in on as a way to specifically address endo and other gender disabilities. Situating the artistic research within the context of painscapes enabled communication of the inexpressible; visibility of hidden pain experiences; reclamation of agency for my/her painful body; and ultimately, an increased awareness

regarding endometriosis and female lived body experiences. In alignment with numerous other painscape initiatives in the last decade, this research placed particular emphasis on producing an external manifestation of pain, bestowing upon it a materiality it would otherwise lack (Tarr in Gonzalez-Polledo & Tarr 2018: 243). The focus was on creating with and through pain - using the idiosyncrasies of the endometriosis experience as material and impetus - rather than solely dwelling on the challenges around expressing pain or gendered disability experiences.

While the concept of using art to navigate personal suffering and identity is not entirely groundbreaking, menstrual, feminist, disability, and crip art are still contested spaces, demanding more attention, respect, and energy. As discussed in Chapter 1, entrenched patriarchal paradigms and sociocultural taboos around a range of women's health related topics (including menstruation, abortion, miscarriage, fertility, infertility, IVF, pregnancy, postpartum periods, motherhood, menopause, chronic pain, and gendered disabilities) continue to hinder open engagement with these domains. Individuals seeking to explore and integrate the breadth of their full identities and lived body experiences — spanning gender, reproductive health, pain or disability — still confront engrained stigmatisation and pigeonholing. My bundled experience, as endo sufferer, artistic researcher, and performer, provided valuable insights into exploring certain facets of these contentious arenas in terms of identity, ethics, and methodology. These reflections influenced the inception, evolution, and broader contextualisation of the project.

As described in Chapter 2, the establishment and amplification of endo-centricity within the painscape practice involved fine-tuning the research's methodological framework to creatively encompass feminist/crip inquiries and identities. In this endeavour, which deeply coincided with the artistic practice, intersecting ideas and experiences were pinpointed across a range of lenses including dance, feminist, feminist disability, and crip studies. This entailed distinguishing improvisation as a theoretical and practical underpinning for endo-centric research; determining the notion of interruption as a framework for understanding gendered disabilities and pain; and exploring crip identity and crip theory in relation to the practices and ethos of painscape art-making. Identifying the interconnections between improvisation, interruption/female lived body experiences, and crip theory clarified the research approach, ethics, and practices. Consciously cultivated and creatively explored, overlapping practices/perspectives, incorporating adaptability, presence, heightened awareness, somatic consciousness, collaboration, and bodymind inclusivity, were integral to the research design's evolution. Forging an interdisciplinary and intersectional path for endo-centric painscape research supported the prioritisation of the wisdom that originates in endo bodyminds and shifted attention towards honouring and engaging with that wisdom in a creative, respectful manner. This research approach and improvisational arts practice defined by feminist crip pathways and perspectives became an outcome in and of itself.

Intertwined with the methodological framework, the research's creative practices, delineated as Phase I, II, and III, were introduced in Chapters 3-5. These art-making methods — including

improvisational experimentations with dance, visual and performance art, and writing, as well as the integration of other women's stories through collaborative duets and public-facing performances — collectively represent a crucial research outcome. Through a feminist crip painscape practice, these methods revitalised articulations and understandings around endo experiences and present a framework for the sharing of endo stories. Moreover, the methods showcased female pain and specifically, endo pain, as powerful material for generating painscape art as evidenced in the most tangible research outcomes: the exploratory painscape portfolio and the various painscape layers of *Nether Space(s)*.

Furthermore, embodying a feminist crip ethos in painscaping uncovered wider dimensions of endo experiences, which might be leveraged as a way to reframe or crip narratives surrounding identity, female embodiment, chronic pain, disease, and disability. The explorations and resultant artworks led to profound inquiries into ideas surrounding crip futurity and resilience, challenging conventional dualities of coping versus curing. How can endo warriors or any individuals who face incurable, chronic conditions nurture a sense of wholeness amidst their brokenness? How might stories of pain evolve into stories of acceptance, healing, or connection? While the research may not provide definitive answers to the above questions, it did increase visibility and validation of our bodies' narratives and journeys. The personal transformative capacity of the research through visibility and validation will be addressed in the ensuing section of this chapter when I delve into my research-related experiences of catharsis, transformation, and healing.

More broadly, from what I have encountered, witnessed, and experienced in this research, 'feeling seen, heard, or felt' might be a requirement when approaching themes related to coping, healing, acceptance, and/or resilience. Increasing visibility in institutional, educational, and public spheres not only supports personal pathways for new knowledge, learning, growth, and progress for those suffering from endo as well as those who are unfamiliar with or not impacted by it. For example, beyond pain communication capacities, the solo painscape performances in Phase III and the culminating painscape performance of the *Nether Space(s)* offered implications in terms of providing care and support for those individuals living with endo and endo's residue. Indeed, the public performances became a beacon of hope for future community building, support system development, education, and public outreach dimensions of research beyond this project. Although not a primary aim of this project, these insights, divulged below, encompass invaluable areas of impact and potential directions or applications for this research and for painscape and crip art research more generally.

Like other painscape research, *Nether Space(s)* and the entire body of work in this thesis provide specific versions of pain, bringing particular realities of endometriosis and pain into visibility, audibility, and palpability (Tarr in Gonzalez-Polledo & Tarr 2018: 242). As such, the responsibility of any painscape researcher is to continue the collection and communication of pain narratives and experiences across diverse bodies and marginalised identities (Tarr in Gonzalez-Polledo & Tarr 2018: 98). This leads to the potential application and direction of this kind of research in the domain of

social justice and gender equality (which is described in conjunction with advocacy and educational initiatives below).

Lastly, while this project's methodologies, methods, and resulting artistic expressions contribute significantly to the fields of pain communication, narrative medicine, and performance studies by supporting new understandings around endometriosis, the true revelation of this painscape research lies in the emergence of 'netherness' as a conceptual framework. Notably, the improvisational practices characterised above (adaptability, presence/heightened awareness, somatic consciousness) were central to allowing netherness to organically emerge within this research. Improvisation provided a flexible and responsive framework to explore and express the complex, cyclical, and unpredictable nature of endometriosis pain. These strategies enabled the embodiment of pain's transient and often elusive qualities, making the invisible visible and the inaudible audible. Improvisation fostered an environment where the nuances of pain and the lived experiences of those affected by endometriosis could be dynamically represented and continuously reshaped. As such, these improvisational strategies are implicit within a netherness practice, underpinning the creation, communication, and understanding of embodied pain narratives.

Crucially, while netherness was born from prioritising the unique and specific experiences of endometriosis, the framework's core principles — emphasising shifts in body, space, time, and expression — are equally relevant to other chronic pain conditions, such as fibromyalgia, chronic migraine, rheumatoid arthritis, and complex regional pain syndrome (CRPS). As such, I envision engaging with chronic pain sufferers in future collaborations and projects. These conditions share common traits with endometriosis: they are largely invisible, unpredictable, and disruptive, often requiring those affected to reimagine how their bodies inhabit space, perceive time, and interact with the world. Such shared attributes necessitate a framework that considers chronic pain not merely as a symptom to be managed, but as a complex lived reality that disrupts everyday experience and demands new modes of expression beyond the limitations of biomedical discourse.

In this way, netherness serves as a versatile framework for art-making that not only engages with, but also critically interrogates the lived realities of chronic pain across diverse conditions. By providing a platform through which the ongoing disruptions and embodied experiences of pain can be expressed and explored, netherness might also enable chronic pain stories to be shared in ways that transcend individual diagnoses, fostering connections among those with varied experiences of chronic pain. Furthermore, netherness offers an approach to 'crip' chronic pain itself, positioning embodied disruptions as central to rather than peripheral in creative practice. This reorientation invites creative practitioners to foreground the lived, ongoing disturbances that chronic pain produces within body, mind, and expression, thus challenging conventional narratives of pain and illness. In doing so, netherness fosters a deeper engagement with chronic pain as a source of knowledge, agency, and creative possibility, empowering practitioners to create work that reflects the complexities of their embodied experiences.

As a dynamic creative praxis, particularly within the performance domain, netherness revolutionises and expands the possibilities of how art and academia can engage with divergent bodies and of course, pain. As a personal outlook, it has the capacity to shift modes of being, thinking, sensing, and creating to revere and embody the full extent of our identity. By extending its influence across diverse fields and discourses, it enriches and deepens collective efforts to bring female pain experiences out of margins and footnotes. With this in consideration, after sharing prospective avenues and possible extensions of this research as a whole, I ultimately arrive at a conclusive emphasis of netherness and its significant power to shift.

Implications, Applications, and Trajectories for Netherness & Endo Painscapes

Visibility & Embodied Agency

II.

Opening my eyes.

Shifting in my seat.

Bearing witness to

Her body, her battleground.

Black paint

Dripped down her back

Reminiscent of

Last week's

Anatomy class

In the realm of invisible disability and pain, visibility, validation, and solidarity and their intricate dynamics, assume pivotal roles in shaping personal experiences of acceptance, resilience, and coping. Visibility entails the acknowledgment and recognition of individuals' experiences, serving to combat stigma and elevate awareness. Validation reinforces the authenticity of these experiences, fostering a sense of acceptance, agency, and empowerment. Solidarity fosters unity and support among those affected, nurturing mutual understanding and collective action. Resilience encompasses an ability to adapt and draw upon internal and external resources for growth. An arena where visibility, validation, and solidarity can converge, netherness — its perspectives, processes, and outputs — emerges as a source and pathway for well-being, resilience, empowerment, and transformation for endo warriors.

Personal Experiences of Healing, Catharsis, Transformation

First, my personal discoveries suggest that using netherness as a framework induces metamorphic shifts not only in art and research, but in life. In the dual role of witness and sufferer/witnessed, I gained a deeper grasp of the interplay between the sense of validation derived from the communication of shared, marginalised experiences and supporting endo sufferers' journeys towards hope, connection, and empowerment. For example, netherness, which in this research manifested in and through a feminist crip performance practice rooted in improvisation, provided avenues for healing, catharsis, and identity/pain transformation specifically in relation to my struggles with

chronic pain, medical trauma, and infertility. Over the course of this research, regardless of symptoms or peripheral conditions related to endometriosis, the creative process and engagement with others provided me with a wellspring of strength, inspiration, and resolve.

The vulnerable and intimate act of conveying my pain, and the pain of others, through various artistic mediums was empowering. Through art and dialogues, I gained agency and power from pain, reshaping its significance in my life and artistic endeavours. While reclaiming my subjectivity marked a significant milestone in navigating the unpredictability of endo, delving into painscaping within this framework propelled my artistic expression into uncharted territories, notably culminating in the realisation of a nether aesthetic. By the conclusion of the research and performance, I experienced a meaningful sense of creative fulfilment and an overwhelming ‘aesthetic satisfaction of having created an imaginative work’ (Rosen in Gonzalez-Polledo & Tarr 2018: 48).

Apart from the evolution of my artistic voice, my body itself experienced an ardent sense of liberation. Creating and performing in *Nether Space(s)* provided a therapeutic outlet without ascribing to art therapy per se. In particular, articulating endometriosis through creative expression gifted cathartic pathways for the release of embodied trauma and the ‘letting go of negativity’ often associated with catharsis (Belfiore & Bennett 2008). In an embrace and curiosity around the emergence of netherness, I no longer resisted the organic expression of interior sensations and dualities which in the past felt problematic, mundane, or restrictive. In embodying both the beauty and the grotesque aspects of my condition, I unearthed a revitalised sense of authenticity. Moving in and through the murky and tumultuous in-between spaces of my cycles, I found solace in somatic intuition and adaptability. For one of the first times in my life, I resonated with the courage and resilience that others have attributed to my experiences.

In tandem with this personal growth and artistic achievement, the research fostered profound new social, cognitive, and emotional connections between myself and fellow sufferers, as well as with the broader public and medical community. Across various settings and contexts, spanning from Medical Humanities Programs and Art and Healing Initiatives in Hospitals to Endometriosis Support Groups and Academic Departments in Dance and Theatre, I discovered validation, encouragement, and support. This newfound network of support enabled and continues to enable me to navigate the uncertainties of endo with renewed strength and resilience. Breaking the creative silence surrounding my identity and experiences with pain — through the creative process, associated lectures or presentations, and range of performances — provided an avenue to ‘step out of the isolation that pain inflicts’ (Rosen in Gonzalez-Polledo & Tarr 2018:49).

It is important to acknowledge that the autobiographical dimension of this research (the intention of which is first mentioned in Chapter 1) was not without its challenges. The degree of vulnerability inherent in this project and demanded by netherness required the integration of a wide array of self-care strategies alongside or outside of research endeavours. My experiences underline the critical and established need for self-care practices in research involving autobiography, sensitive topics, and

health/pain related elements (Dickson-Swift et al. 2008; Dickson-Swift et al. 2009; Etherington 2004). For instance, the deeply personal nature of delving into my own pain and the pain of others often necessitated moments of temporarily disengaging from the research content or seeking support from a therapy professional to protect my own well-being. In addition, other personal wellness techniques that were beneficial included mindfulness and meditation techniques to manage stress and anxiety and regular physical activity (unrelated to the research content) to promote overall balance between mind and body. Other approaches that posed challenges in my circumstances, but are of significant relevance, involve the maintenance of a healthy work-life balance to mitigate the risk of burnout, as well as the cultivation of support groups composed of individuals or friends who possess a nuanced understanding and empathetic perspective towards endo/art/research experiences (Tillmann-Healy 2003).

Building Community & Support Systems for Others

Next, I observed through multifaceted engagements, including feedback, nonverbal expression, virtual interactions and dialogues within the collaborative art-making, the public-facing solo painting performances, and the initial performance of *Nether Space(s)*, that individuals suffering from endo discovered profound resonance with netherness processes and outputs. Both audience members and project collaborators alike expressed recognition of familiar embodiments of pain and disruption; empathy with the encapsulated emotional states of isolation and grief; and connection to the externalised portrayals of the disease that haunted their own bodies' interiors. These impressions of the audience and collaborators' responses, coupled with my own above noted experiences of empowerment, liberation, and vulnerability offer the essential implication that this research - specifically, the framework of netherness and its resulting processes and artistic outputs — not only supported me, but also, has the capacity to support other endo warriors in their pain journeys. This implication suggests possible applications and areas for growth and development.

Expanding beyond the intricate facets of netherness that elicit profound responses among endo warriors — such as engagement with liminality, scar themes, and non-linearity, or explorations of nether spatialities, temporalities, and energies—other factors including painscape format, audience and collaborator composition, and contextual elements merit consideration for extending its influence and accessibility. For example, creating, presenting, and witnessing nether painscapes in culturally significant locations, such as a formal art museum or university setting, seemed to impart a heightened palpability and gravity towards women's pain and endo. The tangible reality of the affliction and the imperative need for its earnest recognition might be emphasised in contexts where content around menstruation, infertility, pain, or female bodies in general typically remain taboo or concealed. Likewise, the live performance format and post-performance discussion, shared experiences in and of themselves contributed significantly to a profound feeling of being seen, heard, or felt. Indeed, as I did, the endo warriors in the audience seemed to finally feel the acknowledgment of their invisible suffering and by extension, their spiritual, emotional, and psychological pain.

Remarkably, hearing other endo warriors verbalise feelings of validation granted me not only artistic gratification, but also, lifted me through their reciprocated compassion. That being said, I hope to continue producing *Nether Space(s)* and other parts of the research portfolio in non-traditional performance spaces and contexts in order to expand visibility and diversify audiences.

However, deliberate curation of performances tailored for audiences affected by endometriosis or related conditions might optimise the project's impact and depth. This could involve establishing partnerships with OB-GYN offices or women's health networks to facilitate engagement with specific communities. Such alliances have the capacity to magnify the energy and effectiveness of *Nether Space(s)* or other painscape exhibitions/performances. Moreover, these interactions could serve as crucial channels for identifying endo warriors interested in engaging with the artistic process, directly or indirectly, thereby diversifying the voices represented in the research. By placing greater emphasis on audience curation, these performances have greater potential to cultivate connections, foster community, and provide validation to individuals navigating similar experiences.

Additionally, as is my own experience, art-making and engaging with a netherness practice can be a powerful tool in its own right, regardless of the artistic outcome. The processes developed in this research might provide alternative avenues for not only articulating inexpressible pain, but also for processing and coping with symptoms. This might occur, as mentioned, through purifying experiences of catharsis; the transformation and externalisation of pain; or new interpretations or expansions of one's identity and culture. In this research, while working with collaborators one-on-one was impactful and powerful, future projects might consider other approaches to increase opportunities for other endo sufferers to engage with art-making processes. In forthcoming phases of my research, in order to fully harness the potent healing potential of netherness and this project's practices, I might develop various workshops with small groups of endo warriors.

Relatedly, mobilising netherness and the practices/methodologies from which it was born, I plan to further develop workshops by extending the foundational movement, writing, and collaborative modalities developed and employed in this project. Within the poetry workshops, thematic explorations will revolve around scars and liminal spaces, providing creative avenues for exploring a range of experiences such as infertility, surgery, recovery, medical trauma, and gaslighting—areas that received less emphasis at this stage of this research. In the creation of movement workshops, similarly rooted in the principles of netherness, I envision not only syllabi producing innovative choreographic or improvisational material, but also inviting strategies for moving in tandem with or out of pain, potentially offering relief. These tailored movement workshops will be specifically designed to meet the needs of individuals undergoing IVF or post-medical procedures, providing them with specialised support and avenues for holistic healing.

Notably, as this research demonstrated, virtual engagement and online spaces can provide opportunities for storytelling, artistic expression, and community building, particularly for individuals who may face barriers to accessing in-person events due to geographical or health-related

accessibility considerations. In general, the exhibition of painscapes, discussion groups, or collaborative workshops on digital platforms could reach a broader audience and facilitate ongoing support and connection.

Finally, perhaps in the expansion of artistic modalities, whether solo, duet, or workshop formats, the addition of an arts therapist might provide another layer of support as individuals grapple with the resurfacing and reshaping of often traumatic experiences. The intersection of painscape work and art therapy presents a rich opportunity for exploration and healing within the realm of chronic pain. Painscape work, with its focus on visual representation and embodiment of pain experiences, shares common ground with the principles of art therapy, which utilise artistic expression as a means of processing emotions and promoting psychological well-being. Incorporating art therapy techniques into painscape work can offer additional layers of support and insight for individuals navigating the complexities of chronic pain. By introducing an art therapist into future iterations of this research, participants can access specialised guidance and facilitation to deepen their engagement with artistic expression and enhance their coping mechanisms. Through guided art-making processes, participants may find new avenues for self-expression, emotional processing, and symptom management. Furthermore, the presence of an art therapist can provide a supportive environment for participants to explore difficult emotions and experiences, fostering a sense of empowerment and resilience in the face of chronic pain challenges.

III.

Breathing fast.

Moving slowly.

Aching deeply.

Tense fingers

Press the colours

Into the wood

Twisting and pulling

As I revisit

The internal grotesque.

Can they see the monsters

Living here?

Advocacy & Education Initiatives

Nether Space(s) was designed as a painscape; a space in which ‘difficult things – the taboo, contradictory, confusing, and unspeakable – can be shared...’ (Rosen in Gonzalez-Polledo & Tarr 2018: 53). Such ‘difficult’ spaces are important, on a personal level as discussed above, for providing support and visibility for endo sufferers, and other individuals identifying with a ‘non-normative’ or marginalised (queer/feminist/disabled/crip) existence. Providing space, time, and energy for reflection, transformation, and coping on an individual dimension is essential.

However, how might the artist or artistic research destabilise the systems in place that keep the marginalised and the dismissed from being seen, felt, and heard? How do we better equip those not in pain to support those who are? Advocacy and education play a lead role in addressing these issues. Through such initiatives, the potential of netherness extends beyond individuals with endometriosis.

For example, *Nether Space(s)* informed community members about endometriosis as a disease and brought related, often taboo, topics to the forefront — including infertility, menstruation, and generally, women's health/pain. From a sociocultural perspective, the public audience, either visitors to my studio or performance attendees, with little to no prior experience or knowledge of the disease, gained concrete understanding from the painscape itself and from exchanges related to such. Similarly, in the medical education context, residents or future doctors gained robust insights of the disease extending beyond the medical school curriculum, which typically involves text-based learning, objective data, or brief two hour OB-GYN rotations. In both contexts, whether through verbal exchange, storytelling, poetry, referenced data, or audio clips from my doctors in the score, attendees heard factual information about the disease's characteristics. More significantly, *Nether Space(s)* comprehensive and authentic expressiveness revealed: the severity; the debilitating physical impacts; the disorienting emotional states; and the uncertainties — of a prevalent yet often overlooked disease. Such an embodied painscape educates the public and/or medical community by inviting them to see, hear, and most importantly, feel our pain. These kinds of shared creative experiences can elicit deeper understanding, empathy, and compassion.

Other uses could include curriculum integration across disciplines, ensuring that students or practitioners in fields such as medicine, art, sociology, and gender studies gain a comprehensive understanding of endometriosis and chronic pain. Workshops and seminars can be organised for diverse audiences, providing training and education to healthcare professionals, educators, artists, and community leaders on how to use netherness as a tool for artistic exploration while cultivating empathy, activating compassion, and supporting awareness. Such knowledge and articulations could be especially meaningful for navigating encounters with menstruators in pain, whether it be practitioners with patients; administrators or teachers with students; and family members or peers in various social settings.

Community engagement efforts can be designed to bring netherness insights to the public through interactive exhibitions, performances, and discussions in accessible public spaces. Utilisation of digital platforms for outreach can extend the reach of these initiatives globally, creating virtual spaces for storytelling, discussion, and support that connect individuals regardless of geographical barriers. Additionally, artistic residencies and collaborations can foster innovative projects that merge art and advocacy, providing artists with the resources and platforms to explore and express the complexities of endometriosis and other chronic conditions. Moreover, the implicit intersectionality of pain means that netherness and some of the other insights/outcomes of this project might be utilised by practitioners or artists without personal experiences with endo. This research serves as a pathway for

delving into alternate experiences of space, time, expression, and energy with criticality and reflection.

A specific example of an educational initiative included an outcome following the premiere of *Nether Space(s)*. The production was invited to the College of Charleston, sponsored by its Medical Humanities Program, Departments of English, Theatre, and Dance, as well as the School of Humanities. This interdisciplinary sponsorship not only speaks to the project's multi-layered nature, but also demonstrates its capacity to engage with diverse academic perspectives and foster dialogue around endometriosis. Moreover, the decision to collaborate with undergraduate dancers, rather than professionals, exemplifies the educational aspect of the project. Although the dancers did not have personal experiences with endometriosis, their embodiment of netherness invited them to connect with the lived body experiences of endo. Through this partnership, students were creatively challenged and intellectually enriched, while also contributing to the broader dissemination of knowledge and understanding surrounding endometriosis.

Drawing from the criptistemology insights advocated by Johnson & McRuer (2014), which challenges the hegemony of singular perspectives and advocates for the inclusion of diverse experiences in knowledge production, this project embraced a multiplicity of voices. For instance, the intentional inclusion of collaborators and audiences with varying perspectives, including some individuals without endometriosis, underscored a commitment to inclusivity, education, and significantly, the recognition of pain as a shareable and shared experience. In this development and performance of *Nether Space(s)*, I encouraged more open dialogues surrounding personal encounters with suffering stemming from experiences impacted not only by disability and gender, but also by race, class, and sexuality. These considerations elicited deeper creative experimentation and produced an environment conducive to empathetic engagement. While intersectionality was not the sole focus in this research, I continue developing netherness as a praxis space where the intersections of pain, various facets of identity, and privilege might also be purposefully explored. Increasingly, I envision netherness as a way to engage with the transformative and generative potential of 'being with and near disability, thinking through disabled sensations and situations, whether yours or your friend's' (Johnson & McRuer 2014: 134, 141).

Artivism

Upon reflection and particularly after the previous sections around advocacy and education, it becomes clear that this research can be viewed through the methodological lens of artivism. Artivism, a portmanteau of art and activism, refers to the practice of using artistic expressions to promote social and political change. This concept merges the creative power of the arts with the proactive energy of activism to challenge societal norms, foster public discourse, and engage communities in dialogue about pressing issues. Notable references in this field include Tania Bruguera, whose work with 'Arte Útil' or 'useful art' exemplifies artivism by transforming art into a tool of social change (2013). Also, the work by Andrew Boyd and Dave Oswald Mitchell in *Beautiful Trouble: A Toolbox for Revolution*

provides practical insights into how artistic and activist strategies can be intertwined. Likewise, activist intentions are organically embedded in the terrain of crip art as well as feminist disability scholarship. Many dance and performance artists specifically champion similar underlying activist endeavours through their creative work; for example, Axis Dance (<https://axisdance.org/>); Candoco Dance Co. (<https://candoco.co.uk/>); or David Dorfman Dance (<https://www.daviddorfmandance.org/>).

Artivism's emphasis on impacting societal structures and elevating marginalised voices resonates with this research's methodologies which similarly prioritised collaborative approaches and dismissed bodies/identities. As briefly mentioned in Chapter 4, the role of witnessing in the context of artivism is central to how art can serve as a tool for documenting, reflecting, and bringing attention to social, political, or cultural issues. Witnessing through artivism involves not only observing or depicting events as the activist, but also engaging audiences and prompting them to confront and reflect on issues to potentially motivate action. Moreover, artivism aligns with this research's deployment of narratives and artistic collaborations to not only depict the lived experiences of individuals, but also to advocate for greater recognition and understanding of our interruptions. In this sense, it embodies the transformative potential of artivism in academic inquiry. With this being said, had artivism been deployed as the primary methodology, the project might have shifted towards audience and community-focused processes and outcomes, rather than its intended emphasis on creative practice, collaboration, and autobiography.

Painscape research, when strategically positioned in an activist realm, could possess even more potential in raising awareness about endometriosis with a more macro influence. *Nether Space(s)* serves as a compelling example of this potential. The performance and creative process functioned as a channel for communication and advocacy on behalf of the collective endo community, effecting change at both a sociocultural and medical levels. Expanding the realm of painscape and crip performance work through this lens has the potential to yield an even broader impact. Eventually, I intend to leverage this retrospective insight to drive future research explorations within that more community-centred, activist space.

Final Remarks: All the threads

IV.

Tension mounts.

Pliable muscles

Grip

As the scarred body

Teeters between

Past and Future

Stilling itself betwixt

Broken and free.

Here we hold

Space for your

Balancing act.

Here we feel

Her pain.

Six women, hailing from diverse corners of the globe and stemming from varied backgrounds, each leading very distinct lives, were united by a shared thread sewn into the fabric of our individual journeys: endometriosis. The both solo and collaborative expedition of unravelling, witnessing, exposing, merging, and signifying bodies' pain stories demanded levels of vulnerability, courage, and care that I personally have infrequently tapped into as an art-maker. Crucially, I came to understand that autobiographically driven research, particularly surrounding bodily and pain/disability/trauma experiences, may evoke triggers and necessitates empathy and compassion, not only towards others, but also towards oneself. While recognising that this work does not encompass the entirety of the endometriosis experience, it serves to illuminate unique versions of pain while underlining similarities in our lived-body experiences. This research represents a pivotal stride in amplifying marginalised voices and endeavouring to firmly integrate endometriosis into feminist, disability, and artistic discourse in innovative ways.

Endometriosis research is not merely a pursuit; it is an imperative. It stands as a symbol of hope, illuminating and dismantling the entrenched injustices women endure globally. I am humbled and honoured to contribute my own experiences, creativity, and philosophy to this vital cause. I can only hope research like this helps pave the way towards a future where every woman's pain is acknowledged, understood, and addressed. And though prevailing narratives surrounding pain often depict it as a solitary, individualised bodily encounter, we are all situated within a web of corporeal relationships and it is crucial to reiterate the interconnectedness inherent in pain or disability experiences (Shildrick 2009). By acknowledging this interconnected network and the fluidity of experiences that traverse between bodies, the rigid boundaries between bodies with pain and bodies without pain begin to diminish. This dissolution challenges discourses that isolate pain as an individualised phenomenon, reframing it as a collective and shareable experience. In essence, this research holds significance not only for those suffering from endometriosis, but also for those who are not.

As the netherness concept unfolds and continues to evolve, my perspectives towards endometriosis and relatedly, pain, disability, disease, and womanhood — shift. How can such darkness become so enlightening? How can interruption and disorientation evoke presence? I believe the answer is that my pain, her pain, our pain achieves new meaning through artistic expression and creative perspectives. Our capacity to improvise with and through the pain and the tribulations of endometriosis is a seed for resiliency and peace.

This research has not excised any disease. Endo still retains a grip on me — physically, psychologically, and emotionally. An ache lingers in the depths of my lower belly. New cysts form unexpectedly on an annual basis. Memories remain etched into the fabric of my being. Scars serve as

enduring reminders. Nevertheless, this research journey has disrupted my pain narrative in a constructive way. Working intentionally with my pain and with other women's pain as creative material has deepened my understanding of the power of both listening and expressing. The study and embrace of netherness has solidified my rooted trust in the artistic process and in performance in particular as a space and time for both brokenness and wholeness or light and darkness. My hope is by using netherness as a theoretical lens, or indeed a creative realm for the 'otherwise', other artists, educators, and advocates might also delve into the profound insights of the endo bodymind and unearth alternative avenues of existence, perception, and emotion. Netherness is one proposition of what we can do with our pain.

Indeed, through this research, I can only hope the collaborators, other endo warriors, my mother, my late grandmothers, and I are not just connected by the threads of pain and medical trauma, but by threads of transformation, hope, and power. As the architect of netherness, I build a place where pain is admittedly disruptive, messy and challenging. It is here where our bodies linger in the space between high and low, up and down, vertical and horizontal. Sometimes, we slump, we stoop, we limp, we hobble. We cry and feel broken. But also, in this redefined realm of netherness, we feel whole, adaptable, and creative. I invite you, the reader, to contemplate your own bodily experiences through the lens of netherness — join us. We dance here, in our own way, without retribution; always feeling dignified and always feeling seen.

V.

'Brave, Resilient, Strong'

Nice words

Cannot excise

Disease.

Praise is

Not a pill

Easily swallowed.

Head held high,

I receive your empathy.

I cradle your broken parts too.

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APPENDIX A: RAW FOOTAGE OF KINAESTHETIC PAINTING PERFORMANCES

In the event that the reader wants to experience the unedited and full performance rather than an excerpt, this is an archive of the raw footage of the kinaesthetic painting performances.

Video 1 (MEI): Unable to provide full painting performance due to ethics regulations from the Medical University of South Carolina.

Video 2 (CHELSEA): <https://www.youtube.com/watch?v=QJvSkPiOzcU>

Video 3 (TOBY): <https://www.youtube.com/watch?v=2fXNnvjb5OM>

Video 4 (JESSIE): <https://www.youtube.com/watch?v=TIWBqzrOrjI>

Video 5 (DANIELLE): <https://www.youtube.com/watch?v=IpkyX6yek0>

Video 6 (KATE/NANCY): <https://www.youtube.com/watch?v=mcr3ELFCGVY>

APPENDIX B: LIVE EXCERPTS FROM *NETHER SPACE(S)*

This is a collection of raw footage excerpts from the August 2023 performance of *Nether Space(s)* at the Gibbes Museum of Art (South Carolina). Although they are not edited, these excerpts support the edited recording of *Nether Spaces(s)* by providing a glimpse into the ‘liveness’ of this performance. These links correlate to sections mentioned in Chapter 5’s description of the performance score.

Video 1 (Prelude Excerpt)

<https://www.youtube.com/watch?v=JETdjGpc6eQ&feature=youtu.be>

Video 2 (Darkness Excerpt)

<https://www.youtube.com/watch?v=dMXwfgTXybM>

Video 3 (Scars Excerpt)

<https://www.youtube.com/watch?v=X4sPnkKe7h8&feature=youtu.be>

Video 4 (She’s Fine Excerpt)

<https://www.youtube.com/watch?v=RT3dgCX48EA>

Video 5 (Warmth Excerpt)

<https://www.youtube.com/watch?v=wdiuJfNWz7U>

Video 6 (Down, Down, Down Excerpt)

<https://www.youtube.com/watch?v=s2pTfyBWM38>

Video 7 (I am Broken. I am Whole. Excerpt)

<https://www.youtube.com/watch?v=Jegj2vlvyhM>

APPENDIX C: USEFUL ARCHIVAL LINKS

FINAL ARTWORK DOCUMENTATION (Links also found in text)

***Nether Space(s)* Kinaesthetic Painting Performance Films Catalogue:**

<https://www.feelherpain.com/nether-spaces.html>

***Nether Space(s)* Performance Edited Film:**

<https://www.youtube.com/watch?v=dXJ5yGPDQG8>

USEFUL CREATIVE OUTPUT/PROCESS LINKS (Links also referenced in text)

Digital Movement Archive:

<https://www.feelherpain.com/improvs.html>

Digital Phase I Painscape Archive:

<https://www.feelherpain.com/painscapes.html>

Digital Performance/Dance Film Archive:

<https://www.feelherpain.com/films.html>

Digital Rehearsal/Choreography Archive:

<https://www.feelherpain.com/process.html>

Video Essay Summary of Project:

<https://www.feelherpain.com/>