(Dis)pleasures of Pain

Deprivitizing and Coping with Chronic Pain through BDSM

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Abstract

This study aims to explore how the relationship to pain and the body can differ in different context, and how the relationship to pain can change depending on how you interact and engage with it. The foundation of this study is the accounts from nine semi-structured interviews with BDSM practitioners living with chronic pain, this study focuses on the internal processes of embodiment as well as how interpersonal and intersubjective processes can lay hand to create embodiment through reclaimed agency and control. Using the works of Merleau-Ponty's and Turner's theory on embodiment, as well as theory on the phenomenology of pain, the analysis brings to light ways in which pain can be used to help mend the fragmentation often experienced by chronically pained people. The findings also bring to light the importance of community, care and intimacy, including what obstacles might be present in to reaching it.

Keywords: BDSM, Chronic pain, Embodiment, Phenomenology, Social anthropology

Acknowledgments

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Content

1. Introduction

"Pain is a ubiquitous feature of human experience."
(Kleinmann, 1994 p. 1)

"Is that really a thing?" has been the most common response when I have explained the themes of this thesis. The contradictory nature of it all seems to strike a chord in most people, and it always takes a while to convince them of why I find it so endlessly interesting. The reaction is often something close to a full body shiver; "Oh, I could never do that. Why would someone even *want more* pain?". The contradictions have kept me hooked throughout this whole project, and it keeps fascinating me still. Pain is, as Arthur Kleinmann (1994) so well puts it, a fundamental part of being human, and it will never cease being so.

There is relatively little anthropological research on pain and pain management, and the scope of anthropological focus on pain is wide. Culture influences on how we feel pain, along with self-administered pain as part of culture, has a long history (Strong & Cogburn, 2025 p. 98). In religious practices, pain has acted as a tool to make one closer to God through punishment or repenting sins, or as a way to show dedication or discipline (Vandermeersch, 2008 p. 263). In anthropological studies, pain is a factor in many avenues of research such as birthing or adulthood rituals, in how culture changes how one experiences and expresses pain, in sports and competitive eating (Singh, 2017 p. 128; Cowart, 2021 pp. 80-81, 170-174).

One could say that chronic or prolonged pain exists in a culturally sensitive position in western cultures. It contradicts multiple norms in regard to the western cultural perception of e.g. pathology and ablebodiness or neoliberal values on how one produces and manages worth (Strong & Cogburn 2025, p. 107). Treating it is hard and can be unclear what to do, with Greenhalgh (2001) calling the treatment of chronic pain "one of scientific medicine's most visible failures" (p. 3, as cited in Strong & Cogburn 2025, p. 106).

The combination of chosen pain and chronic, unchosen pain creates an intersection of deeply phenomenological and seemingly contradictory experiences of pain. Studying these experiences, combined with the social and communal aspects of BDSM and sexuality, might help create a deeper understanding of how one understand and navigates an unpredictable body.

This thesis is not about sex per se, but it is about pleasure, desires and disappointments and growth. The purpose of this thesis is to explore how people living with chronic pain use BDSM practices and how those usages can relate to intersubjective making of pain and the relationship

to the body. By using a phenomenological approach to pain and embodiment, I wish to answer the following questions:

1. How do people, suffering from chronic pain, use BDSM practices?

To be able to answer this question, I will also have to answer how people living with chronic pain relate to their bodies and through what social processes their understanding of their bodies is viewed.

2. How is pain negotiated intersubjectively between practitioners within this field?
3. To what extent can BDSM practice deprivatize chronic pain by bridging the gap between self and other?

Background

Chronic Pain

Medically, chronic or prolonged pain is commonly classified as pain that has been ongoing for at least three months. Chronic pain can be the result of many things but is often s often divided into three categories depending on the type of medical reactions: nociceptive, neuropathic and nociplastic pain. Nociceptive pain is often due to tissue damage from e.g. arthrosis or rheumatic illness; neuropathic pain is due to damage or illness on the nervous system. The nociplastic could be explained as where acute nociceptive or neuropathic pain has developed and changed how the nervous system process pain. The nerves become overactive, and initially local pain can increase and become more generalized. Even though 20-40% of adults live with chronic pain, the views on how to treat or ease chronic pain remains indecisive (Allmänläkarkonsult Region Skåne, 2023).

The term *crip* is used as both verb and adjective in critical disability studies. It could be likened to how ‘queer’ is used to describe how one can go against normative perceptions of things, but crip “seeks to destabilize the norms of ableness” (Sheppard, 2024 p. 1). The non-crip approach to pain sees it as “intolerable” and unlivable (ibid., p. 33) and totally disregards the reality that people *do live* with everyday pain.

BDSM

The BDSM community organizes itself using specific terms to communicate roles, positions and interest. To make this organization clear, a short explanation of the terminology used, follows.

By Margot Weiss' (2011) definition, BDSM is an umbrella term consisting of three acronyms:

Bondage and Discipline (B&D) is the practice of restraints and binding. Bondage can range from leather gear like cuffs and furniture like the St Andrew's cross to Japanese rope bondage called *shibari* or *kinbaku,* which is a highly aesthetic and creative practice. The D refers to Discipline and incorporates different types of disciplining action like punishments and positive reinforcements through e.g. spanking and rewards.

Dominance and submission (D/s) refer to a negotiated power exchange and dynamic. A D/s relationship can range in severity and length, from practicing a so-called 24/7 TPE (Total Power Exchange) relationship to shorter, specific role-playing scenarios playing with power. D/s relationships and scenes are based primarily on symbolic power, and how it is practiced can vary greatly in physicality, sexuality and geographical proximity. The uppercase 'D' and lowercase 's' is used to further signal power dynamic in text.

Sadism and Masochism, or *Sadomasochism* (SM) is most commonly used to describe play with sensations and pain. Sadism is to give pain, and masochism is to receive pain. Pain here being the complex keyword, something this thesis will go into in depth.

Although this study is made in a Swedish cultural context, the BDSM scene can be seen more as an international subculture. Being made more visible by pop cultural works like the Fifty Shades of Gray, movies like Babygirl and Pillion and more, the community has grown from more locally managed spaces to more globally recognized, with the biggest internet forum having over 13 million users[1] (Carlström 2016, p. 229). Still, local grassroot organization and individual initiatives are often the primary forces of community (ibid. pp. 91-93). Swedish BDSM forum Diversia Social (DS)[2] currently has almost 240,000 members and is used as a platform to spread information and events, publish blog posts and pictures and connect with others with similar interests.

[1] https://fetlife.com/
[2] https://diversia.social/info.php

2. Prior Research

The themes of this thesis have been dealt with by various disciplines, e.g. gender and sexuality studies, critical disability studies, law and of course medicine. This chapter contains a brief overview of the research relevant to this thesis, with a clear focus on research done by qualitative and ethnographic methods. It acts as a background and has been a steppingstone for this project.

Disability, sex and BDSM

In his book *Loneliness and its opposite: Sex, Disability, and the Ethics of Engagement,* Don Kulick (2015) discusses the sexual rights of disabled persons who engage with different levels of care personnel and whose sexual lives, in some way, are dependent on other actors who are not sexually involved. The book also discusses the prejudice disabled people are met with when discussing disability and sex. Both hypersexuality and asexuality, though thought of as direct opposites, are biases resulting in the sexuality of disabled people being ignored and their sexuality being invalidated (pp. 6-7). Kulick's book is interesting since it highlights the struggles and abuse met when trying to access one's sexuality. Still, it focuses on a slightly different group (disabled people with care personal) and has acted more as a background in this thesis.

Shanna K. Kattari (2014) writes about the intersection of disability and sexual practice. As mentioned by multiple researchers on the subject of sex and disability, there is a culturally established perception of disabled people as asexual and unable to perform their gender (Shakespear et al., 1996 p. 97; Reynolds, 2007 p. 42). Sex is not thought of as a part of a disabled person's life. Using Goffman's (1963) work on *stigma*, this thought might be reproduced and alter disabled person's perception of their own sexuality. Kattari further pinpoints the importance of communication in sex, and how "kink can be used as a framework for establishing communication between partners" (Kattari 2014, p. 508) and can be an especially useful tool in disability sexual practice. The already established social norm of communication in kink or BDSM spaces supported their informants in creating a more well-functioning sexual practice.

Emma Sheppard (2024) is a British sociologist focusing her research on critical disability studies. Her book *Chronic Pain, BDSM and Crip Time* has been at the core of my research from the start of this project. Other than her book, her earlier articles about societal and medical

norms surrounding pain and chronic illness/disability (Sheppard 2018, 2019, 2025) have been paramount in my understanding of the subject. In her book, she studies the effects chronic pain patients get from practicing BDSM, primarily in receiving pain as a part of their practices. Sheppard's analysis on BDSM and pain can be boiled down to three themes: pain as bodily autonomy or agency; pain as tolerance and proving yourself (to yourself or others); and pain as control.

BDSM

BDSM has been studied through various lenses, prominent has been the medical view of BDSM practice. Until its update to DSM-V in 2013, *Sexual sadism* and *masochism* was a part of the DSM-IV, classifying it under paraphilias and thus in the same category as pedophilia (DSM-IV 2000) and the morality and pathology of BDSM and kink has been, and is still being, discussed by various groups. Although the increase in studies on BDSM, probably as a consequence of greater interest in popular culture, few qualitative studies have been conducted on the subject. One study I have used on BDSM in a Swedish context is Charlotta Carlström's (2016) dissertation on the Swedish BDSM community. Carlström puts great focus on the community and its negotiation of the social reality in which BDSM exists. Through interviews, observations and participating in social spaces and events, Carlström's thesis gives a comprehensive overview of the Swedish kink scene as well as the paradoxicality that could be found in negotiation of internal and external power and taboos, relationships and intimacy.

While Carlström centers her research on the social aspects of the BDSM community, Staci Newmahr (2011) focuses on sadomasochism as a tool to achieve intimate relations with oneself and each other. Like Carlström, Newmahr's book *Playing on the edge: Sadomasochism, Risk and Intimacy* highlight the paradoxical nature of BDSM, calling it "subversive and conformist, liberating and constraining, performative and authentic, and misogynistic and feminist" (2011 p. 168). Taking a much more autoethnographic approach, Newmahr uses her own experiences of being part of the BDSM community to discuss relationships and intimacy. Having followed the community for four years and being a participant in the scene (and scenes) herself, Newmahr gives close insight into what happens in the less formal moments, between and prior scenes, during planning of events and more.

Other work used are the work of Margot Weiss (2011, 2006). Her work on BDSM focuses on power dynamics and social hierarchies within the practicing community, and how those coincides with desire, pleasure, embodiment and identity.

3. Theory

This section describes the theoretical framework for the analysis. As it will later be described, theory about pain and embodiment are closely related and thus hard to separate; embodiment can happen through pain. The purpose of this chapter is to explain how embodiment in anthropology works, and how phenomenological approach to pain is advantageous in explaining embodiment.

On the Body

Embodiment

> "I cannot get an outsider perspective on my body, for it is the vehicle through which my perspective comes into being." (Merleau-Ponty [2002] 2005, p.44)

Maurice Merleau-Ponty is one of the foundational scholars when it comes to the body, perception of the body and embodiment. Fraser and Greco (2005) describe how Merleau-Ponty's theories about embodiment can be boiled down to how "...knowledge of one's own body and knowledge of the world can be accessed only *through* the body." (p. 43). This can be interpreted as a constant negotiation of the body through a self-made outside perspective, and how one can create an object of the self. Merleau-Ponty means that one cannot have an outsider perspective of the own body, since it is the perspective one looks at anything and everything with. The duality of *body* and *mind* becomes troubling when discussing embodiment, and although worth criticizing, will not be touched upon further[3].

Using Brian Turner's (2008) notion of treating *embodiment* as a social process through which one creates a corporal form and thus "places particular bodies within social habitus" (p. 245) might be seen as a further (and somewhat simpler) approach. Turner also describes embodiment as an intersubjective process with multiple social actors, something I will return to later.

Working on Feuerbach's (1953) and Goffman's (1963) theories of laboring on the body and body practices, Turner (2008) argues that the body exists as an "environment we practice on and also practice with" (p. 161). Although Turner's focus revolves around anorexia nervosa and body maintenance, it is closely related to how my informants describe experiencing pain and

[3] If interested, read Margot Price's (2015) article about the *bodymind* as well as Sami Schalk's (2018) work on the bodymind reimagined.

desire for pain as a way of maintaining a bodily status quo. Anorexia nervosa is often an act of social and mental control through the means of the physical, the body and eating, and practicing BDSM as an act of control of a disabled body can be seen through the same lens.

Furthermore, Turner describes embodiment as a social process rather than a fixed state. One of these processes of embodiment is through vulnerability, something highly relevant in my informant's descriptions. Vulnerability derives from the Latin word for wound, *vulnus*, something Turner declares a metaphor for frailty (p. 244). Some early meanings of vulnerability include both being the receiver and the giver of the wound, and in extension, being open to the possibility of being hurt. It helps us navigate a social world while also giving us the capacity to sense pleasure through openness to experience (ibid.).

Phenomenology of Pain

The experience of pain should always be contextualized. In a medical context, pain will often be described as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." (Merskey & Bogduk 1994, p. 210). When push comes to shove, pain is a safety measure keeping us alive and those unable to feel pain due to the condition Congenital insensitivity to pain (CIP) tend not to survive their early twenties (Rasmussen 2009). The IASP's definition of pain is one both physical and emotional, and sensing pain concerns both.

Discussing pain as a phenomenological experience unsettles the body/mind duality often presented in a medical context. Drawing on Merleau-Ponty and Sartre, Svenaeus' (2015) take on the phenomenology of chronic pain discusses the experience of pain, rather than the sensation (p. 113). Svenaeus disagrees with Sartre's body as a *psychic* object, that pain creates alienation of the body, and instead presents the idea that illness makes us experience the body through what otherwise is in the background. The body as a physical object able to receive impressions and sensations is created through unpleasant sensations (p. 114). Using Elaine Scarry's (1988) work *The Body in Pain: The Making and Unmaking of the World*, Svenaeus draws a parallel to how chronic pain can be experienced as "being *acted upon*" (ibid., p. 118, author's own emphasis), thus creating an experience devoid of self-control or agency. One way to take back control, according to Svenaeus, is to create *work* to mitigate the pain, and to make the mitigation process a meaningful activity (p. 119).

Intersubjective ways of creating and unmaking pain

Goldstein (2000) writes about how one learns and specifies sensations, namely pain and pleasure. By elaborating on Wittgenstein's theories[4] about sensations and how we feel them, Goldstein assigns sensations *formal properties* in which we name and experience them. Pain is described as a private event made public through outward criteria like facial expressions and thus communicating sensation to others (2000, p. 91). Meanwhile, by giving pain a location, it becomes public. Goldstein uses the example of how teeth are public, making toothache a public event. Using this same logic, chronic pain can become a private event. Unable to give it formal properties, like temporality or locality, it becomes an individual experience that might be seen as unstructured and unnamed, sensed without the ability of control or communication.

While pain and pleasure in themselves are neutral sensations, the social world often defines and values them; pain is bad and pleasure is good. But not all pleasures are good and not all pain bad (2000, p. 100-101). When receiving pain via a particularly intense massage or acupuncture, we contextualize pain differently than when stubbing a toe on a table. Pain accumulated through intense training might be contextualized through both a social and subjective perspective: pushing yourself through pain might, from an outsider's perspective, be seen as an example of discipline and dedication putting that particular pain in a positive light. Pain exists in a social context as much as it exists in a physical context. Following sections will be about intersubjective ways in which one creates and unmakes pain and the social context in which chronic pain exists. Though highly philosophical, I deem Goldstein's theory of learning and specifying sensations relevant in explaining the multiple ways in which my informants negotiate pain and pleasure.

[4] Wittgenstein's theory is based on two identified ways in how one names sensation: The first one is based on noting the intrinsic character of a sensation, put a name to it and continues to use that name to describe the feeling. The second one is based on outward signs: naming sensations happen intersubjectively through expressions and behavior (Goldstein 2000, p. 89).

4. Methodology

The field

An early approach to the field was to reach out to social media forums created by and for people with certain impairments and diagnoses, e.g. Ehlers-Danlos syndrome and hypermobility, POTS and Fibromyalgia. This approach, however, turned out to raise some issues in regard to my position in the field. Prior researchers' experiences with reaching out to chronic pain or disability forums told me that me and my research would be scrutinized. In reaching out to the owners of these forums, I was met with their own views and biases on chronic pain and sexuality. The social stigma surrounding the themes in this thesis created problems in writing with the owners of the forums and these stigma and biases had to be negotiated. Some denied me access since the subject was deemed too sensitive, and some gave me access only after a thorough examination of my stance, thesis and ethical considerations.

In reaching out to platforms catered to the BDSM and kink community, however, I had more luck. The research and thesis subject was met with curiosity and interest. From these forums, I found research participants with various disabilities, impairments and BDSM practices. Something to further note is that many of the participants also live with some kind of mental health disorders, as well as neurodevelopmental disabilities. This is, however, nothing I will analyze further in my analysis, but worth mentioning since it is part of my informants understanding and negotiation with their environment.

Finally, I have used the term *funktionsnedsättning* in describing disability when reaching out to possible informants. Though debated among the community, this decision came from Socialstyrelsen's recommendations on inclusive and precise language[5]. On the same note, this thesis will follow Sheppard's example and use identity-first language[6].

The informants

The material is based on the statements from nine BDSM practitioners living with chronic pain and/or physical disabilities. I have chosen to disregard factors such as gender, age, role taken in BDSM practice etc., a choice derived from this project's time frame, as well as my preferred

[5] https://termbank.socialstyrelsen.se/article.php?tid=812&src_lang=swe
[6] Identity first-language is often used in disability studies when applying the social model of researching disability; i.e. 'disabled person', rather than 'person first language', 'person with disability'. (Kaplan, 2000; Sheppard, 2024)

focus for this thesis being other. Since being diagnosed with "hidden disabilities", such as chronic pain diagnosis, can be a long and tough process where diagnosis can be used to gatekeep medical support and aid, I have also made the choice to include informants without formal medical diagnosis (Sheppard 2024, p. 31).

My informants have different practices and roles within the BDSM experience and *play*[7]; some are more dominant, a role which usually includes elements of physical and/or mental control, and some take on a more submissive role and in such relinquishes control (Carlström 2016, pp. 16-17). A few of my informants take on multiple roles, identifying as switches or sometimes as caretakers, and their practice might differ depending on partner(s), mood or scenario played. But, as my informant Therese points out, these are labels to categorize human sexuality and lack space for exploration and growth, themes very relevant in this thesis.

All my informants live with a chronic illness, pain and/or disability, often more than one and often both physical and mental. For this thesis, I have focused on bodily experiences in BDSM and embodiment. Since chronic pain is not a fixed diagnosis and can range in experience, it has a stigmatized status within the medical community, something prevalent in meetings and doctors' appointments (Jackson, 2008 p. 333). By including both disability and chronic pain, I made it possible for different experiences to make up the gathered material and create direction for the thesis. Though there is lacking social and scientific consensus of whether chronic pain is a part of the disability spectrum, and vice versa; if disability is synonymous with being chronically ill[8]. The ad the participants in this study answered to include both but turned out to be primarily about chronic pain thus staking out the course of this material.

The participants range in age from around 25–60 and a majority of them are white. I have no informants with 'visible' disabilities, this outcome is unintentional but is a narrative this thesis is missing.

[7] Play: A less formal way of explaining practice. One can have a play partner, meaning a partner only in BDSM-scenarios. Can be romantic/sexual but not necessarily.

[8] A majority of the material I have taken part of shows an indecisiveness: chronically ill or pained people are disabled but a disability can be healthy and not suffering in relation to their disability. Susan Wendell (2001) studies this closer in her text *Unhealthy Disabled.*

Data collection

Interviews

My primary research method has been through semi-structured interviews with an interview guide in place. For data collection I choose to give my participants a few options of how the interview would take place. Based on an earlier made trial interview, as well as Sheppard (2024) methods in working with informants with disabilities, I wanted to create an accessible and accommodating data collection method. I have given all my informants the possibility to choose between being interviewed at a place of their choosing, over video call or over text. I have conducted nine interviews: two have been meetings, five have been video calls and two solely over text. Every interview has been followed up with questions raised during the writing of the analysis and these have all been over text.

By giving my respondents the choice to get interviewed via text on the forum we first got in contact, the informants got space and time to answer the questions in their own time and according to their own needs. The written interviews have still been semi structured in the way that the informants have gotten around five questions as a start and then later follow up questions based on the answers. This method of interviewing turned out to create some difficulties in regard to length and thoroughness of the answer, some questions were even answered with disregarding the question on the basis of not understanding its relevance. Another obstacle has been this method's inability to explain a question if not understood the first time, creating lengthy and complicated moments of rephrasing. While the information my informants received prior interviewing explained how the focus was on my participants and their stories, the answers gotten from the writing participants were closer to answers one might find in a survey: They were short and there were no ramblings or monologuing that might help follow the thought process along.

Observations

I have reached out to, and taken part in multiple *munches*, social gatherings for the like-minded and curious. A munch is usually a lower-stakes pub events, where one can socialize, exchange experience and talk to fellow kink enthusiasts, often without any type of actual BDSM-play happening. Had there been more time and a bigger project with time to get closer to the informants and the community, I would have definitely been up to joining in workshops, events and the like. The plan in attending the munches was to get a general impression of the BDSM

spaces available. The plan was somewhat of a success but was not as effective in gathering useful material as I had hoped. Although the material gathered from the interviews raises many interesting points, I cannot help but think a more present observational method would have enabled a deeper analysis.

Reflexivity

Through studying these intersections of disability and kink, this thesis is already working against the presumptions named earlier. Prior knowledge about the BDSM community, terminology and basic understanding of different practices has been enough to raise follow-up questions about the informants' practices. Since this thesis tangents a quite wide scope of impairments, it has also been made a point to ask the informants prior interview about their specific impairments and practices to be able to address them on their individual experiences with their body in mind.

The underrepresentation of racial diversity might be a consequence of me being white. Only two are people assigned male at birth, this is unsurprising, since people assigned female at birth tend to be overrepresented when it comes to chronic pain and other 'hidden disabilities' (Strong & Cogburn 2025, p. 100). Though it will not make out a great part of coming chapters, four out of ten participants are transgender, and a clear majority identifies as a part of the LGBTQ+ community, thus showing similarities to Weiss' (2011) "pansexual BDSM scene". This might be a result of my own relationship to queerness, with my gender and sexuality being visible on the profile from which I posted the ad.

Some theories regarding chronic pain patients talk about how chronic pain creates an othering position for the patient in meeting with doctors or in meeting with non-crips. Imagining pain as chronic, never not being in pain, can sometimes be emotionally taxing for the listener. I'm trying to do the opposite of what Sheppard mentions when she writes about othering in meetings: "...in shying away from hearing about other's pain (because they are then forced to confront the possibility of becoming pained themselves), listeners silence chronically pained people" (2019 para. 18).

I have attempted to create an emotional capacity for listening even though it was sometimes very hard. I worked with empathy over pity and used my knowledge from my early community counseling workshops-days and validate, but sometimes, the conversations go dark. In those situations, like when my informants move close to what might be interpreted as suicidal

ideation. Hannah Arendt (1998) wrote “Often the most painful experiences are the most privatized” (p. 51) and so I try to remain calm and in different ways show that I understand and there is no judgement in the space I’m trying to create. I don’t want my interviews (or my thesis for that matter) to be similar to either doctor appointments or meetings with able-bodied prejudice.

Ethical considerations

Although no written consent has been given, as it is hard to do so in anthropological studies, information about the study and what might become relevant in participating was given through written information (Davies 2008, p. 55). The informational text regarded the participants rights during all parts of the project, how the information given would be used, what they could expect from me (and vice versa) as well as more logistical alternatives to data collection.

Since the data collected contains information regarding my informants that might be deemed sensitive, measures to ensure anonymity have been taken: any non-relevant information regarding e.g. location or age have been kept private and the informants have all been given pseudonyms that have been used throughout the whole project. Although I have collected a brief overview over my informant’s medical history, this, or any specific diagnoses, will only be disclosed if not relevant. The data has later been transcribed and translated by me. If quoted directly, the informants have been notified and asked if the translation is representative of their original answer, ensuring the informants have power over their statements.

5. Disposition

Following chapters are intended to interpret and analyze the data gathered during the course of this project. Through combining the data with the previously presented theoretical framework I aim to explore how people living with chronic pain use BDSM as a mean to negotiate their position in relation to pain. This section is divided into three chapters:

The following chapters 6-8 will be presenting the empirical material gathered. Starting with chapter 6: *The messy baseline,* I present the foundation of my informants experiences with their bodies in everyday life and in BDSM scenarios; *Doing pain, together* explores how pain, both the chosen and unchosen, can be negotiated between actors in a BDSM scenario and what intrapersonal processes are at play; *Community and Limitations* examines the role of community and what obstacles exist in reaching it. Lastly, a conclusion in which I try to present a set of answers to the research questions.

6. The Messy Baseline

"Cripping is a particular and particularly messy act. To crip, to claim crip, embraces a multitude of meanings-making and claims-making, but I want to argue that crip is also an undoing, a multitude of taking apart, of rupture and disruption."

(Sheppard 2025, p. 2)

In this chapter, I lay the groundwork and discuss how my informants view their bodies in context of existing social norms. I will start with mapping how the participants describe their baseline bodily function and feelings connected to it in everyday life and in BDSM. Following this, I will explore how norms regarding power dynamics and physicality affects the informants' changing bodies and function. The chapter ends with a brief section discussing gender and sexuality, two factors playing additional role in how my informants experience their bodies.

Living with a body in pain

"You learn to live with a three or four … But when the pain gets higher than a six, seven or higher, then I hate the pain. It's the worst there is. I don't understand, I don't want … but then it gets to the BDSM pain, and it can be around a six or seven, but I feel: God, this is so cozy, I feel great and I like this, so it's really all over the place"

(Johanna)

The quote above puts words to a consensus put forward in almost all statements collected. This dichotomy of good and bad pain is ever present when I ask them to describe their relationship to pain. All the people interviewed for this thesis lives with almost daily pain, causing impairments in their lives: their work situation, relationships and social lives among other things. Five of the participants were, at the time of the interview, on sick leave because of their pain and burnout. Chronic pain can often lead to different mental health issues, such as depression, anxiety and burnout. It becomes a vicious circle with bad mental health also resulting in worsening chronic pain (Turner & Kelly 2000; Outcalt et al. 2015)

The bad pain is the everyday pain caused by, or central to their disability. Although the adjectives used in a medicalized context to describe the pain's properties (chronic or prolonged) tells us its temporality, it is vague; chronic is lifelong and prolonged is just longer than at first assumed to be. Still, prolonged pain, according to the Swedish public health informational website 1177.se (2025), is when one has ongoing pain for at least three months. But as earlier described, the medical definition of pain also incorporates "unpleasant sensory and emotional

experience" (Merskey & Bogduk 1994, p. 210). Unpleasantness is not always pain, and chronic pain can show up as unwelcome sensory experiences like nausea, fatigue or muscle weakness and that would still be a part of the chronic pain. Almost all my informants describe the chronic pain as "awful", that they "hate it" no matter the level of it. The bad pain is unreliable; it exerts control over them and in their everyday lives. As my informant William describes it:

> "I usually feel like I'm extremely trapped in my body. Having chronic pain makes it so … there's always something nagging, something gnawing in my body, even before I realized I had chronic pain, it was like … I didn't understand I had chronic pain until I was 22, and then I'd already had chronic pain for like twelve years." (William)

There is a bodily vigilance to be expected from living with chronic pain. Chronically pained people often have very high pain tolerance for most of the acute or temporary pain, but lower for the flare ups from the chronic, something highly relevant to the participants whose BDSM practice centers receiving pain (Cowart 2021, p. 25-26). The quote above also discloses how relevant chronic pain can be before it becomes a diagnosis, and the mental toll it can do on someone. Although many of my informants chose to engage with pain, some do not want to have anything to do with it. Tommy, a Dominant and caregiver in his fifties, explains how he shies away from his pain. If something is hurting, then something is wrong and he won't do it anymore. This, however, is similar to other statements and speaks to an innate knowledge of which pain is which, categorizing pain and knowing if it is the bad pain or the good pain. All my informants speak about a bodily awareness stemming from them being in pain for a long time. They know their pain.

Frederik Svenaeus' (2015) work on the phenomenology of pain and embodiment speaks to the way my informants told me about how they strive to gain a sense of bodily autonomy. We are not made aware of our body in any everyday setting, it is through sensations, like pain, we are separated from what is happening outside of us and connected to what is happening in our bodies. The body, Svenaeus writes, "withdraws and so opens up a focus in which it is possible for things in the world to show up to us in different meaningful ways through our actions." (2015, p. 110). Positive sensations, like being hugged by a loved one or touching a soft fabric, initiates a whirlpool of bodily functions (ibid.). Pain and pleasure are not opposites, and the two sensations can and do co-exist, they might even enhance an experience. In the following part, I will investigate how my informants experience receiving pain and what this means for their sense of self.

The Purpose of Good Pain

> "It is through experiences such as pain that we come to have a sense of our skin as bodily surface, as something that keeps us apart from others, but as something that also 'mediates' the relationship between internal or external, or inside and outside."
>
> (Ahmed, 2002, p. 19)

The bad pain stands in opposition to the good pain and in interviews some of my informants have had a hard time talking about the good pain as pain. Medically, it is the same signal communicating to the brain: signals communicating tissue damage are transmitted to the central nervous system with the help of different nociceptors (Leknes & Bastian 2014, p. 59). However, pain is not dependent on nociceptors and some signaling from the nociceptors, like when eating spicy food, is not always recognized as pain. In the same manner as an intense massage or an ice bath post sauna can be nice, pain-like sensations received in a positive context is received in a positive manner.

Agency

In the testimonies of my informants one can understand the good pain, in a BDSM setting, as giving a sense of control. Using pain to control external factors like pressure, internal factors like mental health or practice self-discipline in e.g. religious practices is, and has been a common in many cultures, rituals and other kinds of social processes throughout time (see Cowart 2021). For the informants calling themselves *masochists*, those who enjoy receiving pain as a part of their BDSM practice, the good pain is not always categorized as pain but rather pleasure. It is a sensory experience and somatic experience with multiple purposes. Almost every informant interviewed describe the everyday pain as "awful", that they "hate it" no matter the level of it[9]. Their everyday bad pain is unreliable; it exerts control over them and in their everyday lives, managing chronology (see Sheppard's (2024) *crip time*) and is not only an unpleasant sensory experience, but emotionally unpleasant as well.

This unreliability is part of something Svenaeus (2015) describes as *being acted upon*. Living with chronic pain removes the agency from the person, making them abject in their own bodies.

[9] Pain becomes an almost separate entity in their lives, a shadow following them being prevalent as they are vigilant.

It is both embodiment and disembodiment at the same time. For some, engaging in kink can act as pain control, and by that, exerting bodily agency. For William, the precarious situations he puts himself in is a way for him to exercise bodily autonomy. Through finding a space within one's embodiment to be able to feel the whole body, without the need to turn down or actively ignore certain sensations becomes a way for him to connect with his whole self.

Self-awareness on how one's body feels and works is something William applies in meetings with medical practitioners. He explains to me how communication in medical scenarios has been improved by practicing communicating physical and mental sensations and experiences in BDSM contexts. "Knowledge is power", he says to me, further proving how kink negotiations and structures around kink can be used as a tool to communicate and deprivatize pain in multiple settings. Honing communications skills is something multiple informants mention, e.g. with Johanna getting a space where her needs and limits are met and respected. Veronic's communication skills have also improved because of BDSM negotiations and discussions acting as a space for her to practice. She is implementing those skills in her everyday life, using them in her work as a teacher, raising the importance of consent, communication and respecting other's boundaries to her students.

Control

If a part of the enjoyment of BDSM is to exercise agency over one's body, control is another. Though agency and control might seem very similar, they are discussed differently in statements. Playing with pain, regardless of what type of play, is a way one can control the formal properties of pain. By choosing what type of pain one wants to experience; stingy, thudded, deep, sharp etc., it's temporality; when it starts and ends, the mood in which one receives the pain and who administers the pain, you become in control of the pain you will experience. You could also put an end to the pain via communication. The pain one receives in kink can be the opposite of the chronic pain my informants suffer from. As Sheppard (2024) puts it, BDSM becomes "… a space to speak back to the pain." (p. 91) and thus taking control over it.

"A thing that gives me a great feeling of control when it comes to receiving pain in a BDSM-context is that, for the moment, I have chosen the pain. It gives me a degree of control, it's not just pain my body gives me that I cannot redirect and just have to relate to. Instead, it's an experience I have chosen and can enjoy."
(Samuel)

Additionally, controlling how one remembers the experience, often via bruises and markings, is a part of being reminded of one's bodily autonomy. Informant Veronica explains how bruises work as a reminder of the scene they come from:

"… I know I did this with myself and to myself, there was purpose and consent and safety."
(Veronica)

The strong body

As in any culture, there are norms and expectations tied to roles and structures. The BDSM community is no different and norms regarding power, physicality and gender in connection to living with chronic pain, is a topic raised in multiple statements.

Prior to getting sick, Therese's dominance was focused primarily on physical dominance. Her interest in BDSM started in her teenage years and when she later started practicing herself, she found joy in the restricting elements of bondage and shibari. Getting to tie her womanhood to strength was something she took great pride in, and when she got sick in her late twenties with a condition resulting in muscle weakness as one of its symptoms, she had to rethink her practice.

"I became weak and it was very difficult for me to relate to ... I'm still working on this. That no, my physical strength was not there anymore, and it was a big part of my identity that I could do things, that I was so strong and then all of a sudden, I couldn't anymore."
(Therese)

With her strength diminished, she started to question her role as a dominant. She reflects on how she earlier thought of dominance as a physical practice, but how she has had to relearn that with her body changing. For Therese, this journey of self-rediscovery has been both positive and negative. In the beginning, she tells me, she felt insecure in her role since she had issues doing things that had earlier been an integral part of her play. Practices like suspension[10] play or moments interacting with gear with fiddly locks were not a given anymore and preceded to put her in a position of insecurity. Today, she lives with her partner she describes as "quite vanilla", and though it has caused her to rework her practice together with her partner, it has also given her space to experiment. Through experimenting with kink, similar in how she and many others started their practices, she has gotten the possibility to "broaden her toolbox" and try working less with the strength of a physical body and more with the mental domination and

[10] Suspending someone in air and a part of shibari bondage practice.

power exchange. The transition from a more physical to a more psychological dominance, she explains, has been noticed by play partners and the feedback she's been given has been positive, noticing the change in practice and praising her for her calm and self-assuredness.

Mio, a *shibari* rigger and workshops leader, have had pain in their hands and back for the bigger part of their late adult years as a result of physically taxing jobs. Mio found their way into the BDSM community through a Swedish internet forum and got an invite to join a *shibari* workshop as a rope bunny, instantly getting hooked to the feeling. Starting their journey into kink later in life, the expectation placed on riggers and rope bottoms alike got clear in interacting with the wider shibari community. Mio tells me about a shibari course they recently attended:

> "Basically none of the course participants could do [the positions] because they were too physically advanced. You have to be very fit, like an acrobat or gymnast, to be able to be in the positions they had so then we thought OK … but why is everything adapted to those who are completely physically capable? It's absurd. Everyone has little flaws and such … But now, I only bind with people who I feel like, this is a person I enjoy hanging out with. We do ropes together and I say no to everyone else because it doesn't give me much and it also gives me the opportunity to feel capable. I don't have to do things that I can't handle. They don't get shocked if I start crying because it hurts because they know I have problems"
>
> (Mio)

The expectation of a certain physicality needed to practice shibari has made itself known in how the room of workshop is constructed without accessibility in mind. They tell me of times where they must get help in making the room and environment accessible for them, sometimes having a partner help them assert themselves in the room, making the room functioning for them, not the other way around.

Still, there are times when some informants long for a more physical practice. Being restricted by muscle or joint functions and strength and thus not being able to, for example, safely suspend someone in the air can act as an unwelcome reminder of not functioning as one has had. In the beginning of her illness, the pain caused Therese to become insecure in her role as rigger. Afraid that her grip strength would fail her during more physically intense scenes, her body's new function threatened to become an obstacle in performing according to expectations.

> "I didn't trust my own abilities and when you have someone who trusts you so blindly, it's incredibly important to have control. There would be terrible consequences if something went wrong and it was because of me. I couldn't live with that, and so my role as dominant was damaged …I think that, as the submissive, makes it hard to deal with it when you feel that, well yeah, that your dominant is insecure."
>
> (Therese)

William, who usually both *tops* and *bottoms*[11], describes how he has issues being as active as he wants because of his chronic pain, causing him to either not participate as a top or turning to more mental or verbal dominance. Almost mourning the lost possibility to "dick a guy down", William explains to me how much his energy curbs his possibility to partake in a scene. Even as a bottom, which usually can be a more passive role, he cannot be as active as he wants. This is tiresome, he tells me, but not something he has given up on. Through finding community, William is planning to start researching how mobility aids can function in giving people with disability and chronic pain more autonomy and range in how they can participate in kink. The purpose of community is something I will discuss in later chapters.

Gender and sexuality

Many interesting aspects of the BDSM practice as a chronically pained practitioner has been raised throughout the fieldwork and interviews. Though gender was not thought out to be a big part of this thesis, I feel it is worth spending a few moments discussing these themes. There is little research done on the intersections of LGBTQ+ identities, kink and disability (Sheppard 2024, p. 2), possibly as a result of the binary, medical perception of gender, sex and sexuality. The heteronormative approach to disability studies is highlighted by Sheppard (2024) as a result of the reproductive focus on disabled persons sexuality and a by-product of eugenics politics and the fight for, and against, reproductive rights of disabled people (pp. 46-47). Excluding the informants' experience of gender and queerness would be counterproductive in this thesis, since most of the informants view their body during BDSM scenarios through a lens of both their queer- and/or transness and their disability.

Additionally, curating what play partners you are interacting with during BDSM can also be validating to one's sexuality. Ella, who identifies as a lesbian, sees a clear connection between her sexual practice and her sexuality. Living out her fantasies and practicing kink creates a space for her to engage with her sexuality and sexual identity as a lesbian. For her, the body restricts her possibility to be her 'true' self and practicing BDSM gives her space to be true to herself.

> "… it feels like I have to hide myself. I also think it's somewhat related to, because I, I'm a lesbian woman so there are definitely connections for me when it comes to my sexual orientation and being able to live out my kinks and [do] BDSM. So it's very linked to like- I don't want to hide myself. I want to be able to be

[11] Terminology used in the vernacular to describe the active/administering or passive/receiving participant in a scene. Used both in and outside of the kink community. Someone who takes both roles is usually called *versatile.*

me. Genuinely me."

(Ella)

Another aspect of curating play is security. Samuel has been physically transitioning for almost six years and has a complicated relationship to his body. His history with eating disorders, the current prolonged pain and his transness create an ambivalent position to his body were engaging with his sexuality and kink has made him more comfortable in his body. There is an appreciation present in knowing that his body, with all the complicated history it entails, is still a space through which he can enjoy pleasures. Also choosing to primarily play with other trans or non-binary people, Samuel is able to enjoy more intense types of kinks and still feel validated in his body and identity: "The conversation about the body and what feels comfortable is already there". For Samuel, the shared transness creates a space where discussions about power and gender is already established as a natural part of the relationship, claiming a similar approach to communication as Kattari (2014).

Closely related is the question of sexuality. There is a divide in the motivation on why one engages in BDSM: having no interest in *vanilla*[12] sex, Tommy views a relationship with elements of BDSM being of great importance. In this same manner, Johanna cannot imagine a future relationship without kink. For others, however, the main practice is less sexual and more of an intense hobby. When Mio plays during their workshops or at rope events, it is exclusively nonsexual, and they would reject invites for sexual play. This distinction between sexual and nonsexual play is made also by both Weiss (2011 p. 90) and Newmahr (2011 p. 17). Instead, they liken it to an experience more like extreme sports than sex. Carlström (2016), on the other hand, uses Foucauldian theory to view BDSM through a lens of social structures and norms regarding sexuality, sex, reproduction and pleasure. Her informants disclose how they feel the need to be precise in communicating to others if they play sexually or not, and thus works on an existing norm of how one expresses morality in sexual relationships (2016 p. 137-138).

[12] The word used in the BDSM community to describe a normative sexual practice.

7. Doing Pain, Together

In the prior chapter, I explored the internal processes experienced by the informants. If pain, as Goldstein (2000) wrote, is a private event up until that moment one makes it public through communication, e.g. facial expressions, the properties of prolonged or chronic pain make it private to a degree of isolation. Many of the interviewees talk about isolation as a direct result of their pain, something Sheppard (2024) links to the nature of engaging with pain, which can be described as a "threat to the phenomenological self" (p. 13). Research on burnout amongst physicians and medical personal who are constantly engaging with other people's pain and suffering shows that type of engagement takes its toll (Riquelme et al. 2018). At the same time, challenging and reconceptualizing it can redo how you feel and make pain (Leknes & Bastian 2014, p. 60-61). Engaging in SM play, either if it is administering or receiving the pain, creates space for you to engage with pain in a controlled manner. Though I have earlier talked about controlled pain and its purpose and benefits, I have yet to mention the social processes and encounters, that is, giving and receiving pain in a kink context. In this next chapter I will dive further into what can happen when making and unmaking pain together.

To Surrender

Scarry's (1988) *work* applied on the subject of chronic pain is a helpful approach to explaining how pain is managed through intersubjective processes. Doing work is a way one can handle and negotiate one's pain, and doing work together with embodying a *mood*[13], can create space for positive experiences with something otherwise felt negative (Svenaeus 2015). Through creating and facilitating moods, BDSM practitioners living with chronic pain might find a space to recontextualize many of those things otherwise taken away by chronic pain. Following chapter will explore how certain moods can be used to co-create a positive experience with pain. I will also examine how facilitation of BDSM play can be utilized in everyday life and as a part of getting a sense of a changing and unpredictable body.

Svenaeus (2015) draws a parallel from Heidegger's phenomenology on embodiment through feelings by presenting attunements, a "mood-quality" in which things of importance makes themselves known to us (p. 116). We cannot choose what moods we find ourselves in, and we cannot easily change the moods we are in. Chronic pain can be explained through this same

[13] A term used to describe an attunement to feelings (Svenaeus 2015)

statement. Pain permeates our entire being, Svenaeus calls it a "centripetal force [forcing us] to let everything go" (ibid.).

Vulnerability and Trust

The participants in this study having submission as a part of their BDSM practice all have a similar way of describing their experiences. "Being allowed not to think", "shut down and be restarted", "surrendering control" are common expressions when interviewing. In the BDSM community, this "shutting down" is usually called *subspace*. What subspace feels like is highly subjective, but many define it as an altered mental state often described as one being "high of endorphins and adrenaline", getting into a "flow" or an out of body experience (Carlström, 2016 p. 195, 224). Subspace can put you in a vulnerable position, but for many of my informants, it also puts them in a position where their chronic pain is diminished or almost gone. Some explain that this vulnerability is partly what they are looking for in play.

The corresponding term for practitioners on the dominant side of play is called *domspace* or *topspace* and can be described as a 'flow' or 'hyperfocus' (Newmahr 2011, p. 104). Being a top during *needle play*[14] puts William in a hyperfocus where he achieves an almost total focus, making him almost totally unaware of his chronic pain.

For others, the submissive role has become a way to explore self-awareness. BDSM play is built on trust between the active agents. Before playing out a scene, there is often some kind of negotiation or planning happening. Such planning can involve talking about boundaries and limits, what one wants to happen during this particular session (or if one does not want to know), and deciding safe words[15]. This is to ensure that everyone involved is having a good time. This self-awareness is built over time, and it is not always a straight path to explore. If one is a novice on BDSM, it can be hard to know where one's limits go, like in Johanna's case. Having experienced play partners has helped her to explore her limits and boundaries in a safe way. Although she has had experiences where she thought she could keep playing but where her partner has interrupted play based on noticing Johanna's limits being met, knowing that someone can when she is ignoring her own limitations has made her more trusting towards others and herself alike.

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[14] Very much what it says on the tin: you put needles under the top layer of skin, often in different aesthetic patterns. Often described as a very psychological form of BDSM play (Carlström, 2016 p. 195-196)

[15] A safeword is one or multiple words used to communicate needs during scene or session. Despite the name, safewords can also, be actions or gestures if verbal communication is unavailable.

Intimacy and Joy

Vulnerability is a part of creating intimacy, and according to Turner (2008), an openness to both hurt and hurting. Sometimes described as ‘energy’ or ‘connection’, Newmahr’s (2011) informants in the Caeden SM community in San Francisco explore intimacy through play in a similar manner to the informants in this thesis. Sharing a space and time to show up raw for each other, naked in more than one sense, is partly what can make pain through BDSM play such an intimate experience.

> “Through immersing oneself in the potential for violations of trust and body and mind, still other access is granted—through this access, intimacy is constructed.”
>
> (Newmahr, 2011 p. 185)

Intimacy is also expressed in Samuel’s experiences of specifically pain oriented sessions. Getting to experience a buildup in pain is a big part of the intersubjective experience for him. Samuel likes to push himself and challenge his pain tolerance, but that is sometime thwarted by his already existing pain.

> “A big part of my BDSM practice is about the interaction and experiencing [the pain] together. So that's the downside of already being at a higher level of pain because we haven't gotten there together. We can pick up and continue from there, but we've missed the beginning a little bit.”
>
> (Samuel)

Intimacy through expressing joy and playfulness is also a common denominator for many. When asked what emotions and feelings her BDSM play brings out in her, Therese’s answer comes quickly; topping in play brings out an almost childlike joy and creativity. Rope bondage is often creative in its nature; playing with patterns and positions sometimes followed by photographing the results. To Therese, being able to express herself and her practice through crafting elements and preparation becomes an important part of the play.

8. Community and limitations

"… care means moving together and being limited together"
(Price, 2015 p. 279).

In this part, I will explore how BDSM practices and the community surrounding the scene helps deprivatize chronic pain, as well as the importance of community and what obstacles exist for my informants in reaching community. Lastly, a rundown on how the practical terms of BDSM can act as a tool in facilitating close relationships and building care structures.

To be Cared for

Building Community

One way in which one combats isolation is through community. Multiple interviewees touch on a wish to find other practitioners living with chronic pain. One informant explains how the BDSM scene has given her space to accept her being different, how it has made her trust other people in another way than earlier. For her, BDSM is already on the outskirts of what is considered normal and it makes other 'abnormalities', in this case how she explains her everyday bodily function, less weird.

This community of other BDSM practitioners, but not necessarily play partners, plays an important role for multiple informants. Informant Ella tells me about how her online community is part of her practice. Through telling each other about scenes one has done, teasing each other, she has formed friendships with other kink enthusiasts. These kinds of friendships are also relevant for many informants[16]. Mio tells me how they have gotten to know most of their current friends and close relations from the BDSM scene. Kattari's (2014) mention of using kink as a structure in which one communicates becomes relevant in most relationships between Mio and their close relationships. As Mio explains it when talking about how their relationships, made from being a part of the BDSM scene, differs from prior relationships:

"When you do BDSM, you need to talk about what you want, and you have to be open and honest. You must be transparent ... there's no unspoken expectations, just transparency."
(Mio)

[16] The significance of online communities for chronically pained and/or ill people could be its own thesis and not something that will be further discussed here!

Therese also has< a hard time “going back to the vanilla world”, because of the dichotomy between the culture in BDSM contra the “normal” world[17]. It is present enough to cause a clash in open-mindedness and what is regarded to be stigmatic. Johanna tells me how she now has many friends with similar interest in BDSM, and how much easier it is with those friendships, where she is not expected to hide her interest in BDSM.

Accommodations and Accessibility

For William, the wish to find other chronically ill BDSM practitioners partially stems from seeing how inaccessible some things are and wanting to change that. Furniture, gear and event spaces are not at all made with different bodily functions in mind. Although the purpose often is to put someone in a strained position as a part of the play, it might be limited by how one reaches that position, if it puts weight in the wrong place or is in other ways inaccessible to even use. Gear, like harnesses and corsets, are often based on, or very similar to, already existing medical gear. Much like Cooper (2022) writes about her experience with other professional dominatrixes using aids as a part of play, William wishes to make aids more common in play (Cooper, 2022). After all, corsets, canes and tight-fitting leather or latex clothes can all double as both fetish- or kink gear and aid and are a quite common occurrence found in play parties or other events. Mio decided, after seeing how many *shibari* events and workshops were seemingly targeted to a very able-bodied crowd, to start their own workshops. Their workshops are very well appreciated, and the purpose is to create space for “ordinary bodies” with all their flaws and shortcomings.

Spaces made for low easily socially accessible events are, like Cooper (2022) notes, not chosen with physical accessibility in mind. During fieldwork, I joined in on three munches in two different towns in Sweden. All three of them took place in the basements of bars, with narrow stairs leading down to the space where the munches were happening. Although the munches were separatist, with either LGBTQ+ people or non-cis men as the primary target group, the events were visited by 10-25 people. No ‘straight’ munch was visited during fieldwork and therefore I cannot comment on accessibility during more those munches. At one of the events, at the end of a munch, the discussion about accessible kink and play spaces came up. The organizers weighed the pros (the space being free of charge to anyone who could promise they

[17] Many BDSM practitioners use words like rejects, perverts, abnormal, unnatural etc. when talking about themselves in BDSM spaces as a reclaiming to their sexuality and practices being seen as taboo by large society (see Carlström 2016; Newmahr 2011; Weiss 2011, 2006)

would buy food and drinks) against the cons (semipublic space, inaccessible and bad acoustics), but found no good solution before it was time to leave.

Though important with accessible venues, many informants have issues even getting to the events. Chronic pain can in many ways lead to a sort of pain project manager position for the person. Meaning, you must manage every detail of your life to even be able to live it somewhat comfortably. Ella's unemployment and the cost of travelling for going to events creates an obstacle for her.

Unpredictable bodies

Another obstacle mentioned by many informants is the planning needed in getting to the event, participating and then doing the journey home. It might not be obvious for everyone, but many details need to be ironed out for Ella, Johanna and others to be able to attend a play party, club or munch; How will I get there, and will I have any energy to socialize, play and have fun after the journey? Will there be space to decompress or lay down? What can I do not to crash too bad after a scene? How do I get home and what will I need to make this excursion have as few consequences as possible?

All these questions need to be considered before so they will be able to take part of the more social aspect of the BDSM community. This leads to them often becoming dependent on partners to help them and make the outing as accommodating as possible. Johanna's former play partner used to do the "project managing" for them to be able to go to events together. Living with a partner with a similar impairment as Johanna, he was able to help her and could anticipate her needs and help planning for what might come up.

Some of my informants seem to have more predictable bodies, they know what to do and not to do in a scene to avoid too great consequences in relation to their chronic pain. Others, with more unpredictable bodies and impairments, must negotiate the possible consequences of playing. For Johanna, taking the consequences, the time and effort it takes to recuperate after an especially intense session or event is worth it. Johanna explains how she negotiates the rebound she gets after going out and how it for her gets balanced between living a life and not:

"For me, that implies that I could take a day when I'm actually able to go out, maybe go to a club and have a session with someone and live like that, but that I'll afterwards get a real bad flare up and will be bedridden for four days. But I could've also done nothing and be in bed for five days"

(Johanna)

Her being chronically ill and having limitations in energy is something that often keeps her from doing certain activities. Ordinary everyday events, like going shopping, is not something she can do easily. Everything becomes a risk assessment where needs, wants and limitations have to be negotiated, but for her, the outlet she gets from playing is worth the risk.

9. Conclusion

In this thesis, I have explored what role chosen pain can have in the life of a chronically pained person. I have done so by interviewing people living with chronic pain who also practice BDSM. The questions this thesis aimed to answer were:

1. How do people, suffering from chronic pain, use BDSM practices?
2. How is pain negotiated intersubjectively between practitioners within this field?
3. To what extent can BDSM practice deprivatize chronic pain by bridging the gap between self and other?

Living with chronic pain might give you a severely complicated relationship to your body, and the first point of analysis established a baseline by which the participants of this study start on. Even though the range of experiences in this thesis is quite wide, many statements are similar. Experiencing chronic pain can cause a disconnect to one's body, while also making one hyper aware of unpleasant sensorium and in a constant state of hyper vigilance towards one's body. This fragmentation of the body and mind is described by several informants as causing them to have a complicated relationship to their bodies and many lives with the negative psychological effects often accompanying chronic pain. Engaging in voluntary pain works in a similar manner, but instead of fragmenting the relationship between body and mind, can mend it. Through being able to control the formal properties of pain, my informants recontextualize it and find space to explore positive effects of pain. Control and agency are two clear themes in why and how the informants choose to engage with pain.

The pain causes the informants to feel like they are losing both agency and control, expressing how they are being robbed of themselves and experiences in their lives. Although similar to many other accounts from studies on chronic pain, my informants find a way to take back control. Playing with pain, restriction, power and other elements present in BDSM play, becomes an outlet where the informants are allowed space to engage with their (and other's) pain on the terms decided by them. The reliability of the chosen pain becomes a way for the informants to exercise agency over a body they otherwise experience as unreliable. For some, doing 'bad stuff' to your body, knowingly hurting, though not harming it, is a possibility for practicing bodily autonomy and exerting power over one's body.

Although the psychological aspects of chronic pain and BDSM are present in all play, the physical aspects also create a relationship to the body. The strength perceived to be needed in

being the dominant actor in play sometimes becomes an obstacle for the unstable and unreliable bodies my informants inhabit. Though some mourn the loss of muscle strength, the innate creativity found in BDSM play has created space for them to explore and grow in their practices. This transitional exploration has been explained to result in a newfound joy for and trust in one's body.

The second chapter was focused on the intersubjective negotiations of pain between the involved agents in play. This meaning, how different moods could help in making 'good' pain and the body available for chronically ill people. Four very closely related moods were named: vulnerability, trust, intimacy and joy. The case on vulnerability is drawn on Svenaeus' (2015) notion of being vulnerable is being open to pleasurable sensations, and it can show itself through sub- or domspace as being able to totally, either surrender to what is happening to you or to total focus and control. These altered spaces are often achieved where there is trust, and trust is often found through communication about boundaries and vulnerability. Vulnerability is being open to being hurt, but also opens us up to other sensations, like pleasure. Engaging with sensations with a body otherwise associated with suffering helps my informants to feel whole, as wholeness, for them, cannot be experienced in loss of agency. Intimacy is reached in being able to be vulnerable and trusting in a play scenario. Through transgressing boundaries together, intimacy is created. In this intimacy, the informants find space to explore one's body as able to receive and operate through pleasures, desires and joy.

The third and final part discussed how interpersonal relationships and community could be used in counteract the isolation often following chronic pain. The BDSM community is important for my informants, but physical social settings can make community inaccessible in more ways than one, making it hard for disabled people to take part in them. Financial factors, travel possibilities and preparation factors in when planning to take part in an event. While low threshold events, like munches, are more accommodating regarding financial needs, it is harder for those spaces to accommodate towards different needs in function. Alternative routes to find community could be done through online communities, as Ella does, or creating your own space for playing, as Mio has done. Creating in a space one can curate after one's specific needs is partly how some accommodate the practice for themselves. While facilitating accessible spaces is one thing, more work has to be done in regard to gear and furniture.

To sum it all up: engaging with pain through a controlled setting, like a BDSM scene, can help mend the fragmentation of the self that is often a phenomenological consequence of chronic

pain. Finding ways to interact with one's body in a positive and pleasurable context could also benefit the relation one has to one's body. Additionally, sharing pain with others can act as an antidote to the deeply emotional part of isolation.

Lastly, writing this thesis has been a journey, and there has been a lot I have not managed to cover. For future research in this area applying a stronger intersectional- and crip approach would further strengthen the phenomenological discussion around voluntary and involuntary pain. Another avenue of research would be to depart from the phenomenological track and study more practical aspects of embodiment for disabled kinksters, such as gear, fetish and other types of non-pain related BDSM.

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