

EXTENDED [TEXTILE] SOMA: SOMAESTHETICS OF BODILY DISCOMFORTS

Arife Dila Demir



Estonian Academy of Arts, 2023

EXTENDED [TEXTILE] SOMA: SOMAESTHETICS OF BODILY DISCOMFORTS

Supervisors

Prof. Dr. Nithikul Nimkulrat (OCAD University)

Dr. Kristi Kuusk (Estonian Academy of Arts)

External Examiners

Prof. Dr. Kristina Höök (KTH Royal Institute of Technology)

Dr. Vasiliki Tsaknaki (IT University of Copenhagen)

Opponent

Dr. Claudia Núñez-Pacheco (Umeå University)

ACKNOWLEDGEMENTS

Many lovely and inspiring people entered my life and supported me on this journey. Thank you all for being there and exploring with me. I am grateful to everyone and everything that made this possible.

First, many thanks to my supervisors. Nithikul, thank you for your belief in me and encouragement; Kristi, thank you for your endless support and always introducing exciting new opportunities. Additionally, I would like to thank the doctoral school of the Estonian Academy of Arts for supporting my journey.

Many sincere thanks to all the amazing people I met during my year visiting KTH. Kia, thank you for your kind guidance and for welcoming me to the IxD team, and also for being one of the examiners of this dissertation. Claudia, thank you for being an inspiration and contributing to the growth of this dissertation by being a peer reviewer for three of my case studies as well as for being the opponent. Jooyoung and Kristina, thank you for being amazing friends and research collaborators, thank you for exploring discomfort with me. Nadia, thank you for being a lovely friend and helping me out in the soft tech room with the knitting machine when I needed it. And Stacy, thank you for your kindness. Finally, Vincenzo, without whom I would not have been able to create the final artefact of this dissertation; thank you for being my creative collaborator and friend; I am excited about what is in the future for us.

I would like to send my regards to the other peer reviewers and examiners of this dissertation. Danielle Wilde, thank you for challenging me with your thought-provoking ideas and questions in my first peer review event. Vasiliki Tsaknaki, thank you for being my peer reviewer in the second case study and being the second examiner of this thesis. And Michaela Honauer, thank you for being one of the peer reviewers of the final case study and providing invaluable insights.

I would like to thank Hans-Gunter Lock, who always helped me when I needed technical support.

Many thanks to Nesli, who shared my pains and curiosity, who bore with my venting outs, and who became a lovely friend on this journey.

I thank the beautiful and inspiring women who have been in my life for so long. To Sena, thank you for being an amazing friend, sharing my anxieties, and having writing sessions with me from Munich. To my lovely friend Özge, with whom I shared my PhD journey, thank you for being the test listener of my presentations and supporting me. And to Cansu, whom I bother with my questions about psychology, somatic approaches, etc., thank you for the insightful conversations. Finally, to Kuzum with whom we care and support each other.

I send my thanks to Artun, who travelled on trams with mannequins and carried all the other stuff to help me set up exhibitions, for always supporting me and for being a lovely friend.

Many thanks to Memo, who also contributed to my first project with coding but most importantly for your generosity and endless support.

Thank you, R., who entered my life in the final phase of my PhD journey, for making me smile and for all the strawberries.

Finally, I send my love and thanks to my big family for always supporting and being there for me. And Mom, whose love I always feel, Seda and Eylül for being amazing sisters, I cannot express how much I love you, and Semoş for your encouragement and generous support, for being an inspiration.

ABSTRACT

Living and being in the world is an embodied experience in which we unfold kinesthetically. In other words, we explore our environment and ourselves through our moving and sensing bodies, our somas. Through our sensory bodies we respond to external and internal sensations, all of which contribute to our meaning-making process by providing insights into our existence and our environments. We may sense pleasant and/or discomfoting internal and external stimuli, amongst which the discomfoting ones almost always demand immediate attention. Some unfortunate individuals experience persistent internal discomfoting sensations that take over the body influencing how they perceive themselves. I call these persistent discomfoting phenomena ‘bodily discomfort’ that disrupts the everyday flow of the bodies and include conditions such as migraine, fibromyalgia, irritable bowel syndrome, depression, chronic pain, etc.

It is difficult, if not impossible, to remove persistent discomforts from the bodies that they invade. Additionally, these phenomena are not merely physical but ingrained in our somas, in our sensory existences. For this reason, the alleviation of these phenomena should not solely focus on the temporal relief of physical symptoms. Rather it should focus on the enhancement of the lived experience of such sensations. By learning how to transform with our diseased bodies we can find new ways of living and being with bodily discomforts and this transformative journey starts with the acceptance of those agonising events. Building kinesthetic dialogues with our diseased selves may lead us to learn how to transform with/for/through our discomforts as we make sense through our moving and sensing bodies.

Accordingly, in this dissertation, I explore the capabilities and possibilities of interactive wearable textiles called *soma extensions* to promote somaesthetic awareness of bodily discomfort. I ascribe two main qualities to soma extensions: 1) mediating movement-based interactions, and 2) externalising the felt qualities of bodily discomforts. I focus on creating bodily interactions that break our habitual ways of engaging with discomfort to be attuned to our discomfoting bodies and to develop new bodily perceptions. In this dissertation, I particularly work with chronic pain as a bodily discomfort. I conduct three creative case studies to scrutinise the somaesthetics of bodily discomfort via soma extensions which reveal peculiar aspects of the main inquiry. Each case study provides methodological and theoretical insights and an artefact, which altogether inform how to design with/for/through bodily discomforts and ultimately form the design programme called *designing with discomfort*.

Designing with discomfort is a close interrogation of the diseased bodies to understand their nuances to translate and explicate them into design artefacts for bodies to communicate with their bodily discomforts and cultivate somaesthetic awareness. In this practice-based dissertation, I first demonstrate *designing with discomfort* through three case studies and then propose it as a design programme. In proposing this programme, I encourage designer-researchers who work in the realm of close-to-body interactions within human-computer-interaction (HCI), specifically in the field of embodied interactions and soma design, and interactive textiles to imagine other ways of being with discomfoting experiences and provide a space to closely engage with such sensations to become anew.



Photograph by Kadri Tiganik

CONTENT

INTRODUCTION

- Problem, Aims and Research Questions
- Research Background and Related Works
- Personal Background
- Defining Pain in This Research
- Structure of the Dissertation

CHAPTER 1: METHODOLOGICAL FRAMEWORK: SOMATIC DESIGN RESEARCH

- 1.1. Research and Design Approaches
 - 1.1.1. Non-habitual Bodily Engagements as a Method for Cultivating Felt Experiences
- 1.2. Data Collection and Data Analysis Tools
 - 1.2.1. Data Collection Methods
 - 1.2.2. Data Analysis Methods

CHAPTER 2: THEORETICAL BACKGROUND: SOMAESTHETIC BECOMINGS

- 2.1. From Movement to Sense-Making
- 2.2. Cultivating Somaesthetic Awareness
- 2.3. Somaesthetics of Discomfort

CHAPTER 3: CASE STUDY 1: SQUEAKY/PAIN

- 3.1. Aims of the First Case Study
- 3.2. Design Process
 - 3.2.1. First Phase: Designer's First-Person Somatic Pain Exploration
 - 3.2.2. Second Phase: Participant Study as an Inquiry to the Somatic Pain Experience of Others
 - 3.2.3. Third Phase: Returning to the Designer's First-Person Somatic Pain Exploration
- 3.3. Reflection on Squeaky/Pain
 - 3.3.1. Affordances and Frictions of Soma Extensions
 - 3.3.2. Tools for Eliciting First-and-Second-Person Felt Experiences
 - 3.3.3. Design Implications for Non-habitual Bodily Engagements
- 3.4. Summary

CHAPTER 4: CASE STUDY 2: CARING COMPANION

- 4.1. Aims of the Second Case Study
- 4.2. Design Process
- 4.3. Autoethnographic Reflections of Participants: Living and Being with Caring Companion
- 4.4. Reflections on Caring Companion
 - 4.4.1. Affordance and Frictions of Living and Being with Caring Companion
 - 4.4.2. Four Design Strategies for Creating Engaging Soma Extensions
 - 4.4.3. Three Levels of Somaesthetic Awareness of Chronic Pain
- 4.5. Summary

CHAPTER 5: CASE STUDY 3: PAIN CREATURE

- 5.1. Aims of the Third Case Study
- 5.2. Design Process
- 5.3. Narratives of Living with Pain Creature
- 5.4. Reflections on Pain Creature
 - 5.4.1. Affordances & Frictions of Pain Creature
 - 5.4.2. Designing with/for/through Pain
 - 5.4.3. Strategies for Designing Engaging Soma Extensions
 - 5.4.4. Inviting the Notion of Lived Time for the Expansion of Somaesthetic Understanding
 - 5.4.5. Artefact as the Non-verbal Communication of Pain
- 5.5. Summary

6. CHAPTER 6: RESEARCH CONTRIBUTIONS: A NEW DESIGN RESEARCH PROGRAMME – *DESIGNING WITH DISCOMFORT*

- 7.1. Extended Philosophy of Somaesthetics – A Theoretical Contribution
- 7.2. Designing with/for/through Discomfort – A Methodological Contribution
- 7.3. Designing with Discomfort as the Design Research Programme
- 7.4. Designing with Discomfort Manifesto

CONCLUSION

KOKKUVÕTE

REFERENCES

INTRODUCTION



Self-Deception

13.03.2012

Illustration by Arife Dila Demir

Being in the world and living is a sensory embodied experience driven by bodily movements that are the source and start of everything; it is through movement that we came into the world and experience ourselves, things, and beings around us. We respond to what we experience and make meanings out of them through our sensing and moving bodies. As we kinesthetically unfold, we develop new sensations, perceptions and insights regarding our existence. Our movements are both influenced by external sensations (e.g., the smell of a flower, the sound of a traffic jam, or the touch of a loved one) and by internal sensations (e.g., joy, hunger, or pain). We act in certain ways as we experience different internal or external sensations; some prompt pleasant experiences, and some lead to discomforting sensations. While pleasing experiences may sometimes remain unnoticed, discomforting experiences demand immediate attention, reminding us of the embodied existences through agony. Neither in the short term nor the long term – we experience sensations of discomfort in our lives.

For many of us who are unfortunate, experiences of discomfort are part of our everyday lives. When experiences of discomfort become persistent, they take control of the bodies that they invade, influencing how they perceive the world and themselves. One of the main problems that persistent discomfort brings forth is that it ruins anticipated future plans and disrupts the habitual modes of being with the body by forcing involuntary changes. I call such persistent bodily experiences ‘bodily discomforts’ that intrude on the daily flow of the bodies becoming the source of their existence (e.g., migraine, fibromyalgia, irritable bowel syndrome, depression, or chronic pain). Bodily discomforts are chronic experiences meaning that the removal of them is hard, if not impossible. That is why symptom treatment is a common approach towards such conditions. However, bodily discomforts are not solely physical phenomena; rather, they are ingrained in people’s sensory existence and require more-than-symptom treatment approaches. In other words, people living with bodily discomforts may acquire relief by learning how to transform their diseased bodies, finding new ways of living and being. To be able to transform with the discomfort, diseased bodies first need to accept the existence of the discomfort and the changes that it brings forth to be able to develop new living practices. I suggest that in building a kinesthetic dialogue with our diseased selves we may learn how to transform with/for/through our discomforts. Therefore, in this dissertation I do not search for the removal or medical treatment of pain. Rather, I consider the alleviation of pain as finding new ways of living, being and transforming with pain. Based on Richard Shusterman’s philosophy of somaesthetics (Shusterman, 2006), I refer to this transformation with/for/through discomfort as somaesthetic awareness. Somaesthetics suggests that cultivating somatic appreciation skills may enhance our lives, and somatic practices such as Feldenkrais, tai chi, or yoga can help us to cultivate such skills through sensitizing us to our sensory bodies (Shusterman, 1999). In other words, somaesthetic awareness is a heightened sensory bodily consciousness where one becomes attuned to the sensory experiences of the body and is able to modulate these experiences. The word ‘soma’ in somaesthetic is similar to the notion of the lived body in phenomenology (Gallagher, 1986; Merleau-Ponty, 2002), which is the moving and sensing body – the subjective self. Both phenomenology and somaesthetics consider humans as living and sensing beings through which we experience the world and generate new meanings and perceptions of ourselves and the things around us. In addition, somaesthetics particularly discusses that through improving our somatic knowledge we can change our lived experiences. I build the thinking and making of this dissertation on these philosophies and consider the body as the sensory moving agency rather than as mere flesh and use the term body and soma interchangeably. Accordingly, I aim to encourage diseased bodies to be attuned to their disturbing somatic experiences to cultivate a somaesthetic understanding of discomfort.

To do this, I explore the ways of prompting kinesthetic communication between the bodies and the discomfort where the discomfort is explicated through interactive wearable artefacts. I advocate that, rather than suppressing the discomfort, we can amplify the felt qualities of it by creating tangible

manifestations of discomfort as extensions of the diseased bodies. For these discomforting bodily extensions, I specifically explore the capabilities of interactive wearable textiles to mediate sensory bodily awareness. Textiles are materials that are close to the body, almost like a second skin; our bodies are almost always covered with textiles, which, through their materiality, alter our bodily perception. When combined with sensors and actuators, close-to-body textiles have a deeper impact on how we perceive ourselves and the world in relation to it. For instance, different vibrotactile patterns can make people feel heavy, relaxed, surprised, self-conscious, etc. (Kuusk et al., 2018), and auditory cues such as creaky sounds promote the perception of back stiffness (Stanton & Spence, 2020); thus, sound-emitting textiles can be used to develop new bodily perceptions. I regard textiles as bodily materials that can reflect implicit bodily experiences by including interaction modalities in their materiality. Accordingly, in this dissertation, I scrutinize the ways to design interactive wearable textiles that are called soma extensions to facilitate somaesthetic awareness of bodily discomforts. I particularly focus on chronic pain as a bodily discomfort. To be clear, I do not search for a remedy or cure for chronic pain or any other bodily discomfort. Rather, I search for new ways of living and being with discomfort. I explore one of the many ways that we can enhance our lives with our diseased bodies acknowledging that searching for new becomings with discomfort might not be suitable for all diseased bodies. My interest in this research is driven by my chronic pain and my ongoing journey of exploring other ways of being with them. Even though I struggle to accept my pain and the changes they have brought to my life, I am in a constant flux of dialogical conversation with them through my bodily movements. This dynamic dialogue has inspired me to explore the somaesthetics of discomfort by engaging with the discomfort through kinesthetic interactions.

With this practice-based dissertation I exemplify how to promote somaesthetics of discomfort through soma extensions in the context of chronic pain through three case studies. Each case study provides insights for designing with/for/through discomfort using chronic pain as an example. These insights on a bigger scale formalize a design programme, based on Johan Redström's (2017) notion of making design theory, called *designing with discomfort*. *Designing with discomfort* is an intimate engagement with diseased bodies to understand their nuances that can be translated and explicated into design artefacts for diseased bodies to communicate with their disturbances and cultivate somaesthetic awareness. *Designing with discomfort* is an attempt to explore other ways of living, being, moving, and designing with/for/through bodily discomforts. Accordingly, this dissertation contributes to the intersecting fields of Human-Computer-Interaction (HCI) and interactive textiles, opening a new space for designing close-to-body interactive wearables with/for/through discomforts. In reading this dissertation, I invite designer-researchers who work in the realm of bodily interactions within HC and interactive textiles to imagine alternatives of being with discomforting experiences and provide a space to closely engage with such sensations to become anew.

Problem, Aims and Research Questions

In the flow of mundane living, we are consumed by the tasks of daily routines, and our attention is fixated on objects that transiently grasp our attention (Brough, 2001). In the midst of this focused flow, disturbing bodily experiences claim the attention of the body, shattering this busy engagement with daily tasks. Through this agonizing interruption, bodily experiences become the central theme of the day and in the case of bodily discomfort, bodily events become the one and only theme of existence. For instance, the experience of chronic pain is perceived as the intervention of an untamed monster that alters the body and diminishes the life world; it builds a barrier between the sufferer and other people, intervenes in the flux of time creating an incomprehensible future (Thomas & Johnson, 2000). Due to the invasion of chronic pain, diseased bodies tend to develop a fear-avoidance model that includes escape from certain activities

and movements driven by the fear of causing pain (De Jong et al., 2005; Vlaeyen & Linton, 2000). In addition to such movement restrictions, chronic pain forces involuntary changes in one's life and takes control of the bodies. It destroys the learned bodily habits such as the way the person dresses, socializes, eats or exercises.

Accordingly, the alleviation of chronic pain cannot solely focus on the treatment of the physical symptom to provide momentary relief. Chronic pain is a complex phenomenon that is not only physical but psychological as well; it is a phenomenon experienced somatically. Therefore, a pathophysiological focus and analgesic medications fail to mitigate the deep suffering of people and solely provide temporary 'episodic relief of the physical pain' (Thomas & Johnson, 2000, p. 685). The removal of chronic pain is not possible where the physical treatment of it only brings impermanent alleviation. To overcome the struggles that are brought on by chronic pain one must create a new relationship with the altered body and new ways of living. Richard B. Hovey et al. (2018) discuss the healing of chronic pain as not learning to live with it, and to be able to do this one must first accept the pain. The acceptance of involuntary changes forced by pain and the impossibility of its removal are explored as a metaphor for healing – 'the gift of pain' (Hovey, 2018, p. 11). In that regard, acceptance becomes a prerequisite for building a new relationship with the diseased body. After acceptance, one can begin to listen to and communicate with the body to find new ways of living and being with pain and caring for the body.

In this dissertation, I search for ways to prompt such communicative relationships between the body and pain. The expression "I have chronic pain" does not mean that the person is aware of the lived aspects of this discomforting phenomenon. Discomforting events are woven into the fabric of everyday life and may not be experienced as unusual sensations. Even though they cause suffering for the bodies that they invade, bodily sensations may remain unnoticed or incomprehensible for the sufferer. Hence, enabling dialogical conversations between the body and pain entails the facilitation of this agonizing experience as a non-habitual event to re-claim attention. To make pain non-habitual, I explore the notion of the extended body, focusing on externalizing this implicit bodily experience to the outside, and therefore expanding the boundaries of the body. To do this, I use interactive textile artefacts that act as a second skin explicating tacit phenomena and creating multi-sensory pain experiences; I call these wearables soma extensions. Through soma extensions, pain becomes unavoidable, leaving bodies no choice but to communicate and correspond with themselves.

Respectively, in this dissertation, I explore the capabilities of soma extensions to facilitate somaesthetic awareness in the context of chronic pain and formulate the main research question as: *How may movement-based interactive textile wearables as soma extensions be designed to facilitate somaesthetic awareness of chronic musculoskeletal pain through mediating explicated interactions with it?* This research question is driven by a research-through-design approach (Savic & Huang, 2014) in which I employ the soma design approach (Höök, 2018) to intimately engage with the discomforting bodily sensations for use in design. In this embodied research, I examine first-and-second-person accounts of the lived experiences of pain, adopting an autoethnographic research (Armitage, 2013; Given, 2008; Turner, 2013).

I unpack this research question based on its particular aspects into three sub-questions and explore these questions in three case studies. Case study methods allow the generation of thick descriptions covering contextual conditions that are relevant to the studied phenomenon through answering 'how' or 'why' questions (Baxter & Jack, 2015). Accordingly, I formalize the main and sub research questions of this dissertation as 'how' questions and in answering those questions I demonstrate one of the many ways of designing soma extensions that can facilitate the somaesthetic awareness of chronic pain.

- 1) *How may the experience of chronic pain inform the designing of soma extensions?*
- 2) *How may soma extensions be designed to promote engaging bodily interactions for people with chronic pain?*
- 3) *How may soma extensions be designed to address the changing needs of bodies in chronic pain?*

These sub-questions should not be seen as separate inquiries from the main one. Rather, they are part of the main research question to develop an in-depth understanding of the explored phenomenon; that is, the somaesthetic awareness of chronic pain mediated through soma extensions. In Figure 1, I represent the reflective unfolding of this research that is initiated via the main research question (RQ). To explore sub-question RQ1, I conduct my first case study (CS1) by moving, making, and reading that results in the first insight (I1). I1 includes elicitation tools for transferring the felt experience of pain into design artifacts, and it informs on the capabilities of soma extensions to facilitate somaesthetic awareness. Accordingly, I1 informs back to RQ, leading to sub-question RQ2 that is then scrutinized through the second case study (CS2), resulting in I2, which offers design strategies for improving the bodily engagement of the soma extensions for people with chronic pain. In doing so, it highlights the concept of temporality in the bodily felt experiences and, by feeding back to RQ, it suggests sub-question RQ3, which I explore within the third case study (CS3). CS3 applies the uncovered design strategies revealed in the previous case, giving rise to I3, which rearranges these strategies and extends the approach to design with/for/through pain and the notion of the somaesthetics of discomfort. By building on the insights emerging in the three case studies, I form the design research programme called *designing with discomfort* (P), which is the main contribution of this dissertation. I present specific contributions of each case study in the respective case study chapters, and I present *designing with discomfort* in Chapter 6.

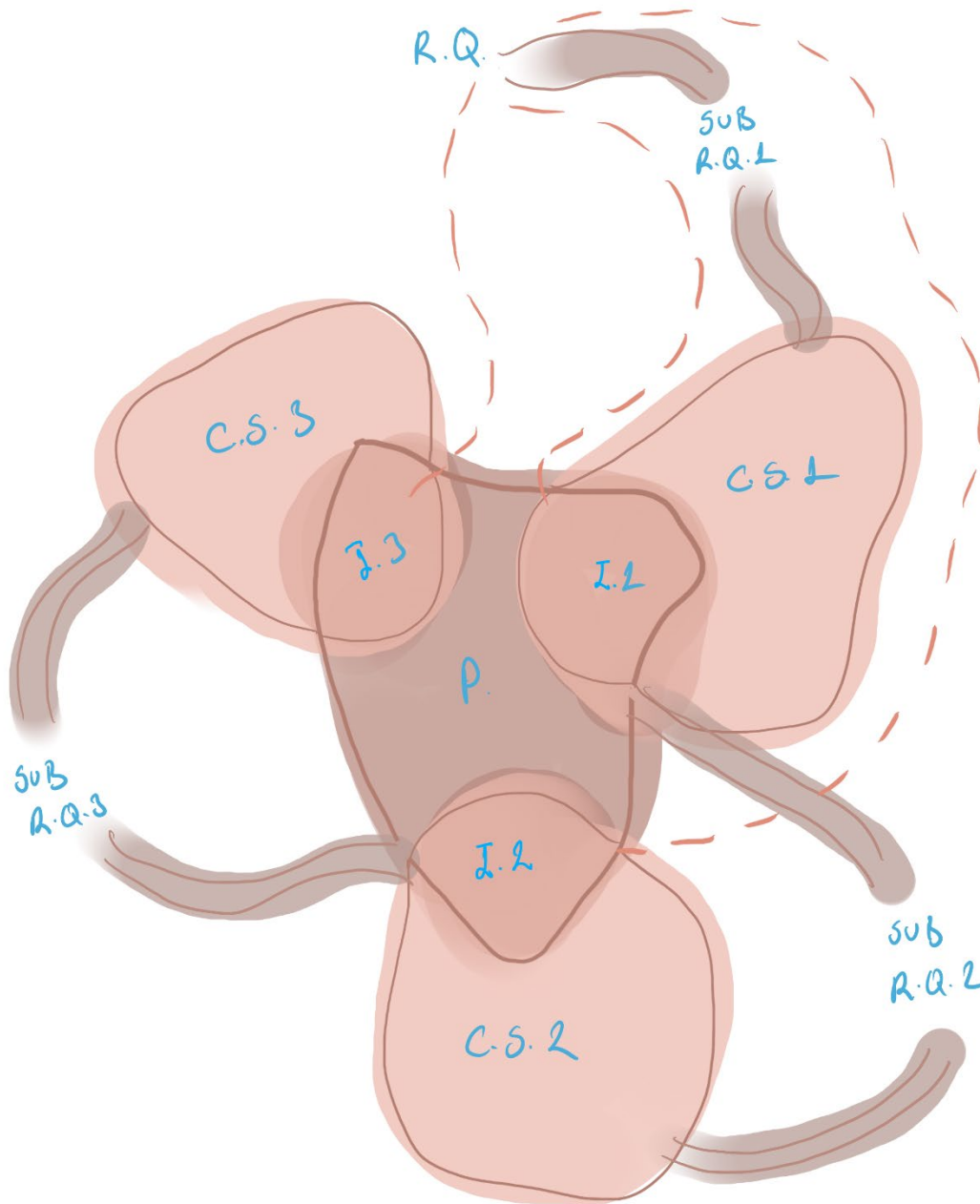


Figure 1. Visualisation of the iterative design process of this dissertation and how this process results in the formation of a design research programme called *designing with discomfort*. Illustration by Arife Dila Demir.

In scrutinizing these research questions, I search for ways of designing soma extensions that may reflect the pain experience. As discussed previously, the main modality of interaction with soma extensions is movement-based engagements. Through movement, we experience the world and ourselves (Merleau-Ponty, 2002; Sheets-Johnstone, 2011) and, in experiencing the world through our moving bodies, develop new perceptions and meanings (Shapiro, 2014; Wilson, 2002). Accordingly, I aim to promote new perceptions and understandings of pain through kinesthetic interactions. In addition, I use sound that reflects pain to trigger movement-based interactions (the idea of implementing sound for movement

interaction first emerged in the first case study that is explained in-depth in Chapter 3). As we kinesthetically engage with ourselves, we generate sounds through our movements that also influence our perception. These self-produced sounds result in a perceptual inference regarding the state of our bodies. When auditory cues are generated outside of the body but are given as sensory feedback towards movement, they still influence the bodily perception when they have semantic associations (Stanton & Spence, 2020). Accordingly, in designing soma extensions I cultivate versatile qualities of pain to manifest the semantic associations of it through sound and material.

In sum, this dissertation aims to explore other ways of designing with/for/through pain as opposed to symptom treatment approaches. It does not claim to provide the treatment or removal of pain; rather, it focuses on the reflection of chronic pain on people's soma; that is, it concentrates on the felt experience of pain and asks prompted questions: What does it mean to live with chronic pain? How does chronic pain intervene in people's daily lives and interrupt their bodily flow? These questions lead me to deliberate on the influence of chronic conditions on people's somas, aiming to understand what kinds of interactions can be designed beyond the problem-solving orientation. In this respect, I attempt to ascertain the transformative qualities of chronic pain to communicate with it as a way to reconnect with the body.

This dissertation uncovers the transformative potential of engaging with bodily discomforts and discomforting interactions, and in particular, to promote somaesthetic awareness through exemplifying the design research process in the context of chronic pain. It shows how bodies experiencing discomfort can be used as a design material for sensory bodily interactions. In doing so, this work invites interactive textile and HCI design researchers to engage with discomforting bodily experiences beyond the symptom-relieving approach and utilize them as material for deeper connections with the body.

Research Background and Related Works

This research is situated in the intersecting fields of HCI and interactive textile design. It is built specifically on the embodied modes of designing interactive artefacts. With the somatic turn (third wave) in HCI, lived experiences, first-and-second-person accounts, autoethnography, kinesthetic explorations, and aesthetic qualities have emerged as essential methods and concepts for the design process (Loke & Schiphorst, 2018). In other words, sensory experiences, how humans move, and what they feel and think in moving have become a source of design, praising embodiment and situatedness. In his book *Where the Action Is*, Paul Dourish (2004) introduces embodied interaction that provides a new perspective on human interaction with digital artefacts. In other words, embodied interaction regards cognition as not solely a process of the thinking brain but as a phenomenon that is ingrained in our bodily capacities. After this first introduction, many bodily approaches have been proposed in HCI as embodied design (Abrahamson & Lindgren, 2014; Tomico & Wilde, 2016a; Wilde et al., 2017), somaesthetic interactions (Höök et al., 2015; Schiphorst, 2009) and soma design (Höök, 2018). These approaches are based on the premises that we move as we sense, and as we move we sense the world and ourselves (Loke & Schiphorst, 2018); as a result of this constant moving and sensing flux, we cultivate bodily perception, cognition, and an understanding of the world and ourselves (Höök, 2018; Loke & Robertson, 2013; Schiphorst, 2009; Wilde et al., 2011a).

On the other hand, as technological materials and sensors become integrated into textiles, the textile design field gets closer to the realm of HCI. There are various definitions of textile technologies that are enhanced by the integration of technological materials. For instance, 'smart textiles' is used to refer to textiles that react to mechanical, electrical, thermal, and chemical stimuli, whereas 'interactive textiles' refers to sensors or actuators interwoven into a garment (Kettley, 2016). Based on this definition, I use the term interactive textiles to refer to interactive textile artefacts that are technologically enhanced with

sensors, actuators, and microcontrollers mediating sensory experiences. Technologically enhanced textiles engage with all human senses; they can gather our bodily information and transform it into data for communicating via various sensory outputs (Pailes-Friedman, 2016). In mediating sensory experiences, interactive textiles can alter body perception helping to develop new bodily understandings. For instance, a dress that mediates vibrotactile stimuli promotes various material sensations concerning body perception (Kuusk et al., 2018), and a light-emitting textile installation that responds to the distance of a person alters self-perception (Demir, 2020). In this dissertation, I work within the field of interactive textiles by combining sensors and actuators in the textiles that support movement-based bodily communication through sound to promote new bodily perceptions in relation to chronic pain. For the creation of these movement-based interactions and the designing of interactive textiles, I adopt the soma design approach, which provides the necessary tools and sources to materialise implicit bodily experiences.

Soma design encourages designers to engage with felt experiences in the design processes and to experience materials through the sensory bodies to better understand the lived qualities of the bodies as well as materials, tools, and concepts that inform, and are used in, design. It then aims at the creation of sensory interactive designs that focus on improving people's life by leading them to get in touch with their somatic selves (Höök, 2018; Höök et al., 2015). Soma design is built on the philosophy of somaesthetics that aims to enhance the body through which we navigate in the world to improve how we live (Shusterman, 2006). Soma is a non-dualistic stance of human existence; it is the subjective self, emotions, feeling, and sensing the body, whereas aesthetics is how we experience and engage with the world through our sensory bodies. Translating somaesthetic theories into the design body becomes the topography of soma design methods. Soma design advocates that designers need to engage with their moving and sensing bodies to cultivate a first-person bodily understanding (Höök et al., 2018). In soma design, the body becomes a site for creative thinking and imagination, and through first-person accounts, designers can cultivate an embodied understanding of the concepts and bodily phenomena that they scrutinize. They can develop kinesthetic empathy, better understand their bodily experiences, and become more perceptive for designing and working with second-person lived experiences.

To acquire such somatic insight, soma design recommends engaging with somatic practices; for example, Feldenkrais, tai chi, yoga, etc., that can sensitize a person to her bodily experiences (Höök, 2018). In practicing somatic exercises, designers can cultivate bodily sensibilities, and learn to better articulate and modulate sensory experiences. Such sensibilities can then inspire the creation of interactive artefacts in soma design processes. Another method proposed for developing bodily awareness is estrangement (Wilde et al., 2017), which is also called moving and making strange (Loke & Robertson, 2013), moving to move (Wilde, 2011a), defamiliarisation (Bell et al., 2005), and non-habitual engagements (Höök, 2018). In addition to somatic practices, by slowing down, one can make familiar daily bodily habits strange (Höök, 2018). Consequently, through estrangement, designers can break the habitual ways of moving, turning their awareness to bodily experiences, and realise otherwise hidden dimensions of the lived experience.

By aiming to design to improve people's lives through mediating sensory aesthetic experiences and bringing people closer to their bodies, many of the soma design projects focus on the facilitation of pleasurable, comforting sensory experiences. For instance, 'The Soma Mat' (Höök et al., 2015) aims to direct awareness inward through verbal meditative instructions in sync with heating stimulation generated by the mat. Similarly, 'The Breathing Light' (Höök et al., 2015) synchronizes one's breathing with the dimming of the light and when used with 'The Soma Mat' mediates a feeling of being taken care of. Schiphorst (2009 & 2010) studies the somaesthetics of touch that mediates pleasant tactile experiences

through the project ‘tendrils’ that generate light and ‘soft(ness)’ that generates vibration, light, and sound when touched. On the other hand, several soma design projects investigate intimate close-to-bodily concepts aiming to promote bodily awareness in relation to the bodily concepts that they examine. For example, ‘Menarche Bits’ supports and brings awareness to the experience of the first occurrence of menstrual bleeding through wearable heat elements (Søndergaard et al., 2020). Similarly, ‘Curious Cycles’ aims to be in touch with the menstruating body (Campo Woytuk et al., 2020), and ‘Pelvic Chair’ attempts to heighten an awareness of the anatomy and function of the pelvic floor through shape-changing soft robotics (Ståhl et al., 2022). Finally, ‘Breathing Wings’ create an awareness of the neglected body parts, specifically the upper body through shape-changing wearables (Tsaknaki, 2021).

These examples illustrate how, through soma design processes, we can design for the sensing and moving body and create awareness of bodily experiences. Many of these examples intimately engage with implicit bodily sensations; that is, pelvic floor muscles or menstruation, which may cause friction and discomfort in design processes during the cultivation of lived accounts of these experiences. Yet, these projects are not explicitly focusing on the discomfort of agonising somatic sensations. Within soma design and HCI in general, few projects focus on discomfort. The notion of ‘uncomfortable’ emerges in first-person explorations through biosensors that provide insights relevant for design use (Umair et al., 2019). Discomfort or the uncomfortable is discussed as intentionally designed to disrupt sensory perception through technological intervention for bodily awareness (Tennent et al., 2020). In addition, purposefully designed uncomfortable experiences are discussed as elements that can benefit cultural experiences – art installations, performances and games – in terms of entertainment, enlightenment, and sociality (Benford et al., 2012).

Uncomfortable explorations in the abovementioned projects do not focus on bodily discomforts such as pain but rather focus on the discomfort that may arise from the wearable artefacts, interactive installations, or performances, or during the first-person explorations. On the other hand, HCI projects that are situated in the context of pain focus on the alleviation of physical pain. Such projects do not consider pain as a somatic phenomenon that requires a physical and mental – non-dualistic – approach to enhance the life of the people who live with chronic pain. They focus on, for instance, developing assessment tools (Hammal et al., 2021; Spyridonis et al., 2016) or monitoring applications (Angelucci et al., 2021). As an alternative to these projects that focus solely on physical support for chronic pain, a smartphone-based device is designed to sonify the breathing and movement during a physical activity to support the performance and motivation of chronic pain patients (Singh et al., 2016). Similarly, in the interactive textile field, the prevalent attitude for designing for chronic pain is based on a problem-solving approach driven by enhancing existing pain therapy tools to improve patient interactions. A quite common tool for chronic pain management is TENS, which applies electrical stimulation to the skin (Sluka & Walsh, 2003). This machine is connected to the body through the sticky electrode pads creating unpleasantness for some. To improve the use of this tool, various textile researchers developed knitted, woven, or embroidered textiles to be used as electrode pads that are more comfortable for bodily use (Erdem et. al., 2018; Goncu Berk, 2018).

However, as discussed previously, chronic pain is ingrained in people’s life; it is a complex phenomenon that does not solely create physical discomfort but influences the psychology of sufferers causing a myriad of problems. It requires beyond physical treatment approaches. One of the problems with experiencing chronic pain is communicating this agonising experience. In that regard, physical discomfort is used to design wearables that can communicate the felt aspects, aiming for emphatic engagements (Beuthel & Wilde, 2017). In addition, tangible pain scales are created as tangible communication modes for this hard-to-speak experience (Fyhn, 2019; Fyhn & Buur, 2020). Similar to these two projects that

consider chronic pain and bodily discomforts as somatically felt phenomena, I aim to design with/for/through chronic pain as a more-than-symptom-relieving approach. To do this, I combine soma design thinking with interactive textile design. In doing so, I gain somatic sensibilities regarding lived aspects of chronic pain that can inform the designing of interactive wearables facilitating somaesthetic awareness. I conduct this somatic research through my textile design and somatic exercise practices adopting research-through-design (RtD) to examine the posed research questions.

Personal Background

At the beginning of my doctoral studies, my research interest was situated in movement-based interactions, somaesthetics, interactive textiles, and body perception with no specific context in mind. Soon after I began my doctoral research, the pain that I was feeling in the right side of my upper back, specifically the right side of my neck, scapula, and shoulders, became persistent. When the tension in my upper back turned into chronic pain, it demanded my whole attention which led me to construct my research in the context of pain. I was particularly interested in exploring the alternative ways of living with pain, understanding its reflections in the life of the sufferer, and its influence on body perception. The experience of pain brought unintentional changes in my life. Not only did it restrict my movements so that I had to adjust my daily yoga practice, but it also ruined my sleep causing uncomfortable sensations and altered my mood negatively in the mornings due to profound tension in my upper back. Around the middle of the second year of my studies, different kinds of pain emerged in my body due to different chronic conditions, namely irritable bowel syndrome and small intestinal bacterial overgrowth.

The emergence of new discomforting conditions made me realise the temporality of the bodies; I came to realise that our bodies are in constant change and to be able to sustain a good life, as much as possible, we need to be attuned to bodily sensations, accept the changes, and explore alternative ways of being. Realising those needs to sustain a good life as a body in pain does not mean that it is easy to achieve them. Living and being in pain is a difficult experience and each experience of discomfort has a different influence on the soma, bringing different struggles to the day-to-day life of the sufferer. On the other hand, I discerned that for the bodies in pain, there is no moment of freedom from agonising events, only that the intensity and qualities of the discomfort events vary daily, but the very existence of the body is entangled with these events. Accordingly, I became interested in how we can become anew and cultivate sensory bodily awareness in the existence of discomforting experiences. I was keen to explore how one can kinesthetically unfold with pain to become anew and how these kinesthetic unfoldings may influence one's relationship with a painful, diseased body.

My interest in movement and how we become anew through moving and sensing is based on my movement practitioner background. In 2013, I started to practice yoga through which I was fascinated to see the hidden potential of my body to perform unimaginable postures as a result of committed practice. Witnessing my bodily potential and how I can extend my repertoire through movement practices altered my perception of my body as well as my worldview. In the year after my first yoga class, I decided to gain an in-depth knowledge of yoga and registered for my first yoga teacher training course. Following that, I participated in various teacher training courses learning different styles and deepening my practice. During my doctoral research, besides yoga, I was engaging with improvisation and dance practices, specifically, I practiced contemporary dance improvisation and the GAGA method (a movement practice founded by choreographer Ohad Naharin). Moreover, I started running, climbing, swimming, and cycling as exercise. Taken together these practices enhanced my bodily sensibilities, improved my interoceptive awareness and my sensory aesthetic appreciation skills. What is alluring about engaging with different bodily movements and extending the bodily repertoire is that not only does it improve my physical bodily

conditions and sensations, but it also alters my bodily experience of the world – being, living and being involved in the world. Therefore, it also influences how I do research.

In addition to movement practices, my research is also grounded on my interactive textile design background. I regard textiles as close-to-body intimate materials that alter the perception of the body. For instance, clothes that are part of our everyday life are an extension of our bodies, and through their materiality, they influence how we perceive ourselves and they influence how we move and sense. With the integration of sensors and actuators, these close-to-body materials are able to mediate multi-sensory experiences, creating a deeper influence on our somas. Accordingly, I combined my movement and textile practices with my interest in bodily interactions and positioned myself as a practice-based HCI researcher in this dissertation. In other words, I situate myself in this dissertation as a human, movement practitioner, textile practitioner, HCI designer, interactive wearable designer, and person who experiences different types of chronic pain.

To sum up, this research is rooted deeply in my felt experience of multiple pains, and my enthusiasm for becoming in movement and interactive textile practice. In the course of this research, movement became the main activity to inspire making, thinking, and researching. I moved with my pains to develop insight into these phenomena. I take my thoughts on a walk, I dance with them, and in turn my writings, makings, and pains influenced how I move, and therefore how I conducted this research. As this research is based on my first-person accounts of pain, in each case study chapter (Chapters 3, 4 & 5) I reflect upon my pain experiences in the section titled *Interlude: Designer's Autoethnographic Reflections*.

Defining Pain in This Research

So, what is pain? Here is a short description: 'Pain is your brain telling you it thinks something is dangerous.'

(Haines, 2015, p. 3)

Chronic pain has no discernable purpose. It is like a very bad habit.

(Haines, 2015, p. 3)

Pain is unavoidable and at times indescribable. It is manifested physically as a strong internal disturbance that consequently also alters the mental state. When we speak about pain or attempt to do so, it usually comes with a discourse of agitation and suffering. Naturally, pain is a bodily experience that is often unwelcome. We do not like to talk about it, we do not like to experience it, and if we experience it, we would like to get rid of it as soon as possible. Yet, it is one of the most common health-related issues that people suffer from and requires a holistic approach to be understood. In medicine, pain is traditionally defined as a physical injury: 1) external physical injury (e.g. a wound), or 2) internal physical injury (e.g. tissue damage, organ damage, etc.) (Biro, 2011). It seems to me that this definition of pain is not enough to cover the various kinds of pain felt by human bodies. Physical pain might occur in the absence of an injury or damage, or might be influenced, negatively or positively, via the mental state of a person; and yet the greatest and deepest psychological pain should not be underestimated. Many scholars discuss the lack of competency in this traditional definition, often from the perspective that it excludes pain that occurs in the absence of physical injury (e.g., fibromyalgia, migraine, lower or upper back pain) (Barrett et al., 2018; Bendelow & Williams, 2008; Kugelmann, 2003). David Biro (2011, p. 108) criticises this traditional definition due to its blindfolded focus on objectivist features, or physicality, of the

phenomenon at the expense of its subjectivist features. Further, he offers a new comprehensive definition: “Pain is an aversive internal experience that threatens to destroy everything except itself”.

In this dissertation, I specifically focus on musculoskeletal chronic pain that occurs due to physical injury and is interwoven with the mental state of a person or vice versa. Pain becomes chronic when it persists for more than three months (Nilsen & Elstad, 2009) or according to different views more than six months (Fyhn, 2019). Most importantly, as Joanna Bourke (2017, p. 3) writes, “[a]nyone claiming to be ‘in pain’ is in pain; if a person describes her experience as ‘painful’, they are”. Accordingly, persistent pain is a great cause of suffering for the bodies it violates, and this torment is different to the experience of acute pain, which is known to claim immediate attention but leaves the body after proper treatment. Whereas chronic pain is woven into the fabric of everyday reality, it is a recurring event that is experienced repeatedly, and it is involved in the formation of the sense of self. Hence, pain as an event is tightly entangled with sensual, cognitive, perceptual, and motivational processes (Bourke, 2017). For that very reason, people with chronic pain are more likely to be interrupted by the pain in their everyday flow, and challenged by the forces that come with it.

As discussed previously, pain is a complex phenomenon, and it cannot be merely seen as a physical event; it is enmeshed in our moving and sensing bodies. Accordingly, the problems that are brought forth by pain are not merely physical, but they cause somatic anguish. Pain can shape movements, influence performance, mood, emotions, and feelings; it can demand attention and distract the sufferer from daily tasks. According to Virginia Woolf (2021), it can shatter the illusion of everyday reality. Even though it is felt within the body, it can be felt like an external force that commands and controls the body causing the diseased body to lose agency and control. Here I will exemplify two major prevailing challenges caused by pain: pain catastrophising and the cessation of the flow of time. I choose to discuss these disputes to illustrate the lived accounts of pain beyond its physical agony, and it is such accounts that the somaesthetics of pain and discomfort aims to alleviate in this dissertation.

Sufferers tend to catastrophise their pains, which is the aggravation of this discomforting stimuli and feeling helpless in the existence of pain. Chronic pain may elicit negative feelings, such as irritation, anger, helplessness, despair, frustration, resentment, etc. The prevailing feeling that emerges with pain is fear, which is the result of the ambiguity of pain and losing bodily capacities (Thomas & Johnson, 2000). Such pain-related fear is one of the significant reasons that influence physical performance (De Jong et al., 2005). When pain enters the life of a person, it brings involuntary changes destroying the habitual ways of being, living, moving, and sensing. For instance, the body that can run, stretch deeply, lift heavy weights, carry grocery bags, or wash dishes can become incapable of performing these tasks. In the existence of persistent pain, one loses the luxury of moving thoughtlessly as the simplest mundane tasks transform into important challenges that need to be carefully planned (Thomas & Johnson, 2000).

Facing the slightest sensations of discomfort moving through the body, pain sufferers may start avoiding certain movement activities for fear of triggering or worsening the pain, even though the movements do not necessarily cause pain in reality. This is called the fear-avoidance model (De Jong et al., 2005) and is associated with catastrophic thinking (Vlaeyen & Linton, 2000). Avoidance leads to an increase in fear that can turn into a phobia, it prevents people from encountering the actual consequences that are often non-harmful, and it may cause disuse syndrome, which is avoiding the use of particular body parts, which can contribute to a pain problem in the long run (Vlaeyen & Linton, 2000). As the experience of pain lengthens, the fear-avoidance model becomes ingrained in a person’s soma, which makes it even harder to decode it. To decode the pain-related fear, the sufferer needs to be exposed to the situations that they identify as dangerous to acquire new information that does not confirm the fear expectations (De Jong et al., 2005); only then can the sufferer re-learn how to move through her body in pain. In this dissertation,

one of the stances of the somaesthetics of pain is to encourage people to move. Therefore, in moving they can explore and expand their bodily capabilities, search for alternative ways of kinesthetically unfolding through their diseased bodies and become new to pain.

When I speak of chronic pain, I do not refer to a constant experience; persistent pain is enmeshed in one's daily existence, yet it is not experienced in the same way. It constitutes temporal qualities, the intensity of pain, and other lived qualities of it changes, for the very reason that it is an ambiguous temporal phenomenon. We experience this ever-changing phenomenon in the flux of time profoundly influencing the perception of time. Things that appear to us to be experienced can swell or shrink time that is elastic in our perception (Brough, 2001). In terms of time perception, we can discuss objective and subjective time. Objective time is universal and measurable with a clock, whereas subjective time is particular and refers to felt qualities of an experienced period. In the experience of pain, time perception dilates leading to a great expansion of subjective time as the pain sensation increases. In other words, time ceases to flow where seconds become minutes, minutes become hours, and hours become days; the now becomes a never-ending period soaked with agony (Nilsen & Elstad, 2009; Rey et al., 2017).

Not only does pain influence the experienced now, it also distorts the retrospective and prospective estimation of time. In other words, it alters people's perception of the present, past, and future, and respectively themselves and the past and continuity of their lives. Everyday tasks are bound to objective time, for instance, work meetings, appointments or social meetings (Brough, 2001), and when pain expands time it intervenes in our ability to perform and 'be on time' for these tasks. It then creates a boundary between the world and the sufferer bringing isolation. For instance, the diseased body might develop anxiety, thinking that others can perceive her as unreliable when she is unable to operate daily routines at work due to agonising pain (Nilsen & Elstad, 2009). Chronic pain is unpredictable and how it will appear every day is a profound question in the sufferer's life. In addition, as pain influences the somatic performativity of the body, it forces changes to future plans. John Brough (2001) describes it as an intimidating closure, a devastating end of oneself and the beginning of the unknown other. In that regard, I am interested in exploring certainties in the unknown by learning to be elastic rather than being rigid towards the changes in the experience of pain. I discuss that in doing so diseased bodies can find the continuity of their lives.

In this research, rather than the physicality of pain, I aim to address the somatic problems that emerge in the pain experience. I focus on examining ways of supporting people and myself, for instance, to overcome the fear of movement and of losing the sense of agency as well as the sense of continuity and of transforming with pain. Within the medical practice, the traditional approach to pain treatment is the use of a medical substance (e.g., drugs, or medical cannabis) (Correll & Kissin, 2017; da Costa et al., 2017; Li et al., 2019). In addition, with or instead of a medical substance, psychological interventions constitute the common practice for managing pain, especially chronic pain. The most common of these interventions is Cognitive Behavioural Therapy (CBT), which has been used as a pain management method (Flink et al., 2016; Pigeon et al., 2012), and Acceptance-Commitment Therapy (ACT), a form of CBT, which has become a more effective and prominent method for pain management (McCracken et al., 2013; Scott & McCracken, 2015; Trompetter et al., 2015; Vilardaga et al., 2020). In addition to these therapies, scholars have studied alternative approaches such as music therapy (Wu, 2017) and physical exercise (Barrett et al., 2018; Waddington et al., 2017) among others. My inspiration to explore other ways of living with pain is rooted in these alternative approaches to pain management.

To sum up, pain is a volatile and particularly subjective event that resists objectification and generalisations. It is not merely physically felt but is experienced through the moving and sensing body. It is connected to our perceptual-cognitive processes influencing how we act, think, move, feel, and sense. It

is the theme of existence for the bodies it inhabits, and it influences the perception of self and brings a myriad of challenges into a person's life. Because it is not only a corporeal problem, the alleviation of pain should focus on supporting the sufferer in a non-dualistic stance that regards people as sensory lived bodies and promotes alternative ways of being and living with pain that is now part of the everyday continuation of diseased bodies. I approach the relief of chronic pain from a somaesthetic viewpoint and consider the cultivation of somaesthetic awareness as a way to mitigate the effects of pain on one's soma. I discuss acceptance as a mandatory prerequisite of the somaesthetic journey through pain that can help one come to terms with the changing body and look for new ways of being. Finally, once again, I acknowledge that pain is a subjective experience and even the same type of pain, for instance, back pain is not experienced equally by two people, nor does it appear constant for the same person every day. I also recognise that the cultivation of somaesthetic awareness might not be suitable for all people experiencing chronic pain. Therefore, this dissertation is my attempt to speculate on the relief of pain through somaesthetics that resonates with me, some of the participants of this research, and others who feel what is proposed in this research echoes with them.

Structure of the Dissertation

This dissertation consists of six chapters in addition to an *Introduction* and *Conclusion* sections. The *Introduction* gives a brief overview of the research and provides the context for the study. The first and second chapters explain the methodological and theoretical backgrounds of the research. The third, fourth, and fifth chapters present the three case studies conducted in the dissertation to explore the research question. The sixth chapter presents the main contributions of the dissertation that emerge from the case studies. Lastly, in the *Conclusion*, I give a brief ending to this dissertation by finishing with the possible future directions.

Additionally, in this dissertation, from time to time I pause analytical writing to illustrate my pain journey and how it evolves in the continuum of this dissertation. In doing so, I place my autoethnographic interludes in each case study chapter and at the end of the *Conclusion* providing a rich and in-depth description of how one becomes new with pain in cultivating somaesthetic awareness. In addition, in the fourth chapter, I share my participants' life stories concerning pain and the soma extension by presenting their re-curated journal entries. Similarly, in the sixth chapter, I present my journal writings illustrating my journey and dialogical interaction with the soma extension regarding pain. The autoethnographic interludes and pain narratives reflected in the form of journal entries are textual illustrations to communicate many ways of somaesthetics becomings with pain. These evocative illustrations inform the design-research process of this dissertation, and they invite readers to the life stories of me and the research participants of this dissertation to think, feel, and experience with us, with people who experience chronic pain. In what follows, I describe the content of each chapter.

Introduction illustrates the research conducted in the dissertation drawing the roots of the thesis from a non-dualistic stance of human existence and stating that this research explores pain as a bodily discomfort. This chapter consists of five sections. First, I introduce the aims of the dissertation presenting the problem area and posing the research questions accordingly. Then in the second section, I give an overview of the context situating the research at the intersection of HCI and interactive textiles and positioning the research in the context of soma design. In the third section, I provide my personal background to explain my motivation, interest, and different roles in this research. After that in the fourth section, I define pain and how it is perceived in this dissertation. Finally, in the fifth section, I provide the overall structure of the dissertation.

Chapter 1. Methodological Framework: Somatic Design Research consists of two main sections describing the structural foundations of this research. The first section presents the research and design approaches of the dissertation. In the first section, I first present my research as an RtD inquiry within which my making and thinking are intertwined in the investigation of the research questions and the roles of the designed artefacts, namely the soma extensions, in answering those questions. I situate my design approach in the soma design field through which I adopt autoethnography as a research approach, thus, engaging with the first-and-second-person perspective. Finally, I introduce the case study research method that is applied to delve into the particular aspects of the main research question. Following this, in the second section, I introduce various data collection and data analysis methods that are used in the case studies of this dissertation.

Chapter 2. Theoretical Background: Somaesthetic Becomings presents the philosophical theories that inspire and inform this research consisting of three sections. I first explain how making and thinking are connected to each other and inform each other in the exploration of the research questions posed. Then in the first section I introduce the phenomenology of movement, embodied cognition, and somaesthetics to explain how humans make sense and develop new perceptions through kinesthetic experiences. The second section discusses the cultivation of somaesthetic awareness referring to Shusterman's philosophy. Finally, the third section discusses somaesthetics not merely as the appreciation of pleasant experiences but also the appreciation of discomforting experiences such as pain and provides an insight into the somaesthetics of bodily discomforts.

Chapter 3. Case Study 1: Squeaky/Pain presents the first case study of this dissertation, which explores the first sub-research question of *how the experience of chronic pain may inform the designing of soma extensions*. Accordingly, in this chapter, I search for ways of cultivating and eliciting pain for design use. This chapter consists of four sections, the first of which states the aim of this case study. This section is followed by an interlude that reflects my autoethnographic reflections on pain, where I share the state of my pain journey during the first case study. Subsequently, I present the design process in detail, explaining how pain is examined through first-and-second-person accounts and how it is translated into design artefacts, namely soma extensions. In this section, I present the design and testing processes of the two iterations of the work *Squeaky/Pain*. In the third section, I make a reflective analysis of the testing and making of the soma extensions. The fourth section unfolds in three parts. First, I portray the affordances and frictions of soma extensions in relation to the somaesthetics of pain. Then I present tools for eliciting first-and-second-person experiences for design use. Following that I provide two design insights 1) creating disturbing experiences in relation to the bodily discomfort in question, and 2) mimicking its qualities through sound to be applied in non-habitual interactions when designing for pain. Finally, in the fourth section, I offer a summary of *Squeaky/Pain*.

Chapter 4. Case Study 2: Caring Companion presents the second case study of this dissertation, which scrutinises the second sub-question of *how soma extensions may be designed to promote engaging bodily interactions with people with chronic pain*. This case study consists of five sections starting with stating the aim of the case study. Before moving to the second section, once again I illustrate my journey with pain and how it unfolds in the second case study through presenting my autoethnographic interlude. In the second section, I give an in-depth overview of the design process where I cultivate a second-person lived account of chronic pain through a cultural probe kit study to understand the ways of increasing the bodily engagement of soma extensions. In the third section, I present autoethnographic reflections of participants who use the *Caring Companion* through narrative inquiry. In the fourth section, I provide my analysis regarding the participants' living and becomings with the *Caring Companion*. I present the reflective analysis of this case study under three headings. First, I discuss different sensory qualities of the

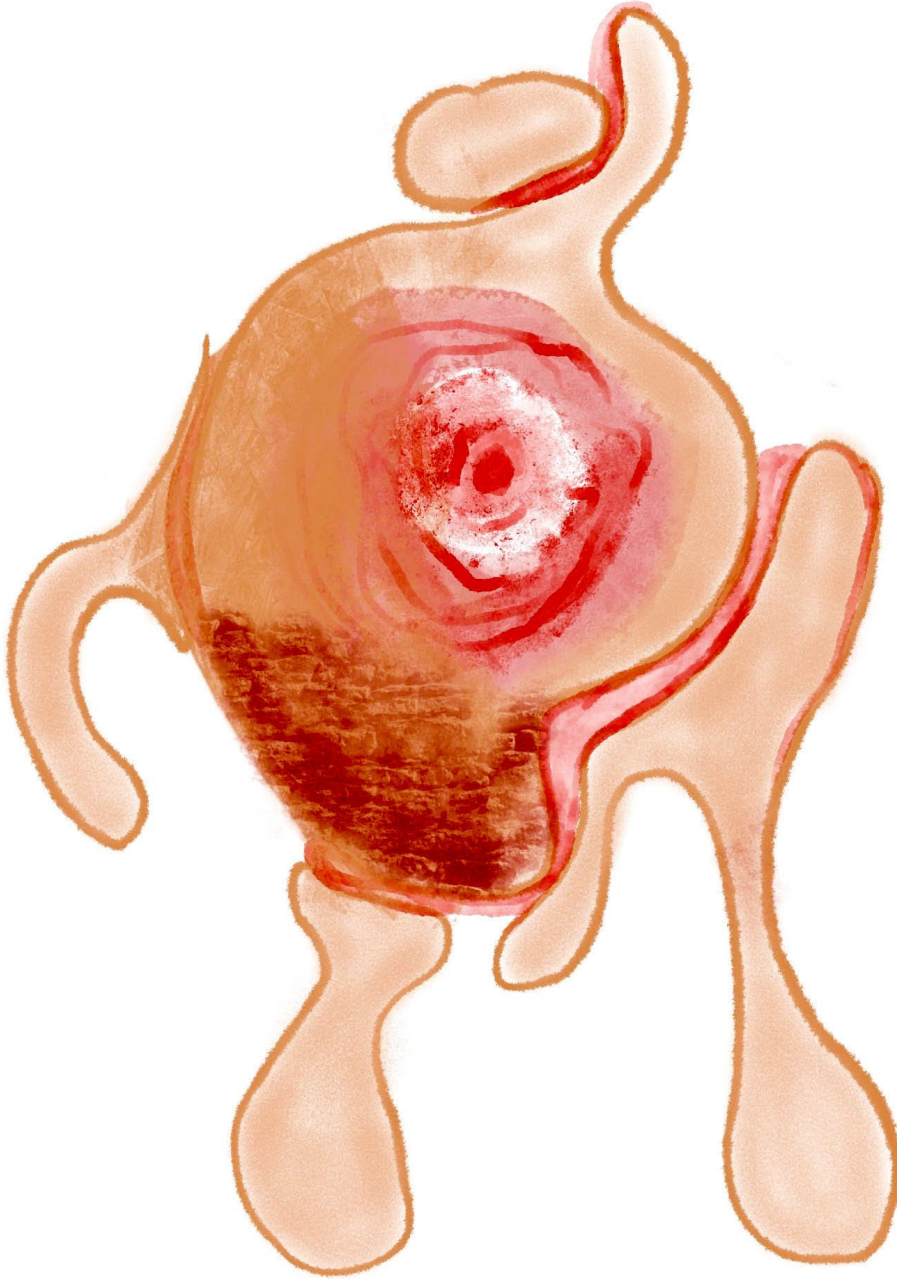
soma extension, its affordances, and frictions in relation to a probe kit. Then I offer four actionable design strategies for designing engaging soma extensions in terms of bodily interactions. Third, I introduce the somaesthetics of discomfort as a three-level journey that starts from diagnosing the discomfort to cultivating self-caring practices. Finally, in the fifth section, I provide a summary of the chapter.

Chapter 5. Case Study 3: Pain Creature reveals the final case study of this dissertation that asks *how soma extensions may be designed to address the changing needs of bodies in chronic pain*. It consists of five sections starting with reflecting the aims of this case study and building connections with the previously conducted case studies. Akin to the previous case study chapters, before the second section I expose my becoming with pains as it emerges in the continuation of this case study via my autoethnographic interlude. Following that in the second section, I give a thorough explanation of the design process of *Pain Creature* that is based on my first-person engagement with pain. In the third section, I present the first-person testing process for *Pain Creature* in the form of a narrative inquiry by presenting my journal writings. In the fourth section, I present my interpretive analysis of my testing and the design of the soma extension. This section unfolds in five steps. First, I focus on the affordances and frictions of *Pain Creature* and discuss the frictions of the testing phase. Second, building upon the previous case studies and the design process of this case study, I present a design approach for designing with/for/through pain. After that, I introduce the reformulated version of the design strategies that first emerge in the second case study and present the concept of subjective time as an extension of the understanding of the somaesthetics of discomfort. Finally, I discuss *Pain Creature* as non-verbal communication mode of pain. In the fifth section, I provide a summary of this case study.

Chapter 6. Research Contributions: A New Design Research Programme – *Designing with Discomfort* presents a design programme called *designing with discomfort* based on Redström's (2017) notion of making design theory. This design programme is composed of the three the case studies to answer the main research question. These case studies bring fourth methodological and theoretical insights into *designing with discomfort* and are exemplars of this design programme. The focus of the programme is designing with/for/through bodily discomforts for facilitating somaesthetic awareness in the context of the discomfort in question. In this chapter, I first explain Redström's notion of design theory and the formation of *designing with discomfort*. After that, I offer the extended philosophy of somaesthetics in the context of discomfort by presenting a three-level understanding of sensory bodily awareness and bring the notion of subjective time as an essential aspect of the somaesthetics of discomfort. In doing so, I illustrate the philosophical stance and the worldview of discomfort design. Following this, I present the methodology of *designing with discomfort* providing various tools and approaches for designing with/for/through discomfort. Then I discuss *designing with discomfort* as a design research programme. Finally, I reveal the *designing with discomfort* manifesto.

The Conclusion is the final chapter of the dissertation. It summarises the whole dissertation and the contributions of this research. It points out future directions that can expand the presented *designing with discomfort* programme. Finally, I conclude the chapter with my last autoethnographic reflections on pain representing how in doing research on bodily discomfort I transformed with my pain.

CHAPTER 1



17.02.2022

Illustration by Arife Dila Demir

1. METHODOLOGICAL FRAMEWORK: SOMATIC DESIGN RESEARCH

In this chapter, I present the methodological structure of the dissertation, explaining the approaches used to explore the research questions posed. This dissertation is an autoethnographic study informed by first- and second-person lived experiences in the context of soma design, which is the design approach of this research. The examination of the research questions is unfolded in three case studies, where the making of the artefacts contributes to the inquiry employing the RtD approach. During the design research process, I used various data collection and analysis methods for cultivating and eliciting felt experiences to inspire the creation of the artefacts and to evaluate the designed artefacts. In what follows, I will first introduce the research approaches and then present the soma design approach. Following that, I reveal the data collection and analysis methods illustrating how and why they were used. Finally, I discuss the notion of ethics and care when designing with/for/through pain through engaging first-and-second-person lived accounts.

1.1. Research and Design Approaches

Design research is a method that tackles the complex set of problems that emerge within the multiplicities of phenomena or require engagements with the unknown. However, there has not been a consensus on what exactly design research and its methods are. Design practice has been coupled with research which traditionally tends to focus on the optimisation of design processes and outcomes (Savic & Huang, 2014) to improve design practice (Cross, 1984) and is perceived as a normative process-focused practice (Kroes, 2022). This traditional view of design research practice extended in different directions, such as “producing knowledge in the area of design problems, methods, and processes relevant to practice, and more recently relevant to the perception of our environment and the general acting in the world” (Savic & Huang, 2014, p. 2). The knowledge contribution of design research does not solely produce design knowledge; rather, it contributes to tackling more general societal and philosophical problems. Such design research is referred to as Research through Design (RtD) with a big ‘R’ that is driven by a pre-defined research question (Frayling, 1993) and leads to discussible sharable knowledge (Savic & Huang, 2014). When Christopher Frayling first coined the term RtD, he freed design research from scientific methods of inquiry, demarcating a place for it where designerly engagement becomes a vehicle for knowledge production (Brandt & Binder, 2007; Markussen et al., 2011). The process of making and creating an artefact is the designerly engagement of research for knowledge contribution.

Research questions in RtD are investigated by the production of artefacts that are “used as a source of data for the analysis and further theoretical development, generalization, formalization” (Savic & Huang, 2014, p. 5). RtD is concerned with informing the research question by making a method of inquiry that focuses on the artefact as a source for knowledge generation. Artefacts confront the status quo prompting discourse around the topic in question; therefore, locating the design researcher as a critic (Zimmerman et al., 2007). Bill Gaver (2012) discusses design and RtD as generative tools that concern exploring ‘what might be’ rather than dictating ‘what is’; therefore, design and art alter the context in which they operate. RtD artefacts are different to utilitarian design products; they are rather conceptual and less functional aiming to extend our perception and knowledge of phenomena. RtD gives agency to the design artefacts, which might as well influence the analysis process opening unexpected doors (Savic & Huang, 2014); such artefacts can help us to deal with unorthodox issues in an unusual way.

On the other hand, RtD is practiced across various disciplines such as engineering, computer science, interaction design, and HCI (Markussen et al., 2011). Since this PhD research is positioned at the intersection of interactive textile design and HCI, as mentioned in Chapter 1, I adopt the RtD approach and conduct this research as an interactive textile designer (Figure 2). Accordingly, in scrutinising the research questions of this dissertation, the design research process unfolds as a performative act where making and thinking are entangled, and the artefacts – the soma extensions – become the sources of knowledge production providing insight into the posed questions. In doing research as an interactive textile practitioner in HCI, my textile background contributes extensive knowledge of materials, making techniques, and the expressiveness of the materials concerning the aesthetics of materials. In return, HCI, specifically body-based design approaches within this field, promotes a set of guidelines, methodologies, and frameworks to conduct interactive textile research that extends its focus to include generating social and philosophical contributions and tackling difficult problems. I advocate that, when designing for bodily interactions, the expressiveness and aesthetic qualities of the materials enrich the experience of the artefacts, while structured methodologies and frameworks help to conduct rigorous research on the bodily concepts in question.

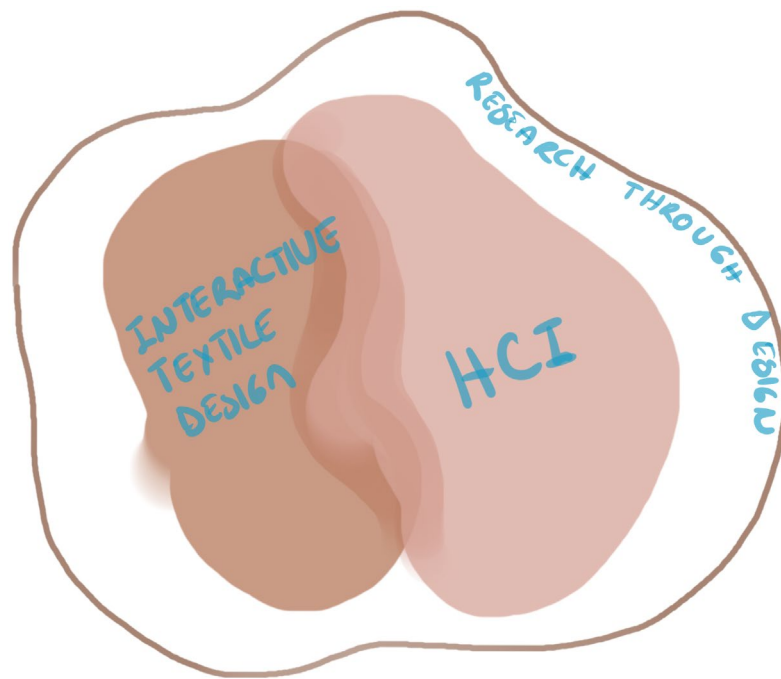


Figure 2. This RtD project is situated at the intersection of soma design within HCI and interactive textile design. Illustration by Arife Dila Demir.

I specifically discuss that embodied design stances in HCI frameworks are complementary approaches for interactive textile research when working with close-to-body interactions. In this dissertation, the focus is on designing movement-based close-to-body artefacts, namely soma extensions. Accordingly, the making process of this Ph.D. research is embodied and performative; it is heavily informed by the felt accounts of pain through the moving and sensing bodies. To conduct such research, I adopt movement-based embodied thinking into making to examine the research questions. In HCI, movement-based thinking is applied as a design approach for designing close-to-body interactive artefacts and/or systems (Höök, 2018; Höök et al., 2015; Loke & Robertson, 2013; Wilde, 2011b). Such approaches emerge from the theoretical directions that consider humans as embodied beings. Specifically, they are inspired by phenomenology which discusses the influence of bodily experiences on meaning-making processes and

humans' perception (Gallagher, 1986; Merleau-Ponty, 2002; Sheets-Johnstone, 1979, 2011). Similarly, enactivism within embodied cognition reveals the importance of the sensory experiences and dynamic interaction of agents with their environments in cognition (Shapiro, 2014) and finally, somaesthetics that suggests developing somatic insight may lead to living better lives (Shusterman, 1999). Some of these movement-based design approaches are embodied design (Abrahamson & Lindgren, 2014; Wilde et al., 2017); moving to design/design to move (Wilde et al., 2011b); soma design (Höök, 2018); somaesthetic interactions (Höök et al., 2015; Schiphorst, 2009) and moving and making strange (Loke & Robertson, 2013). In my research, I particularly adopt the soma design approach (Figure 3).

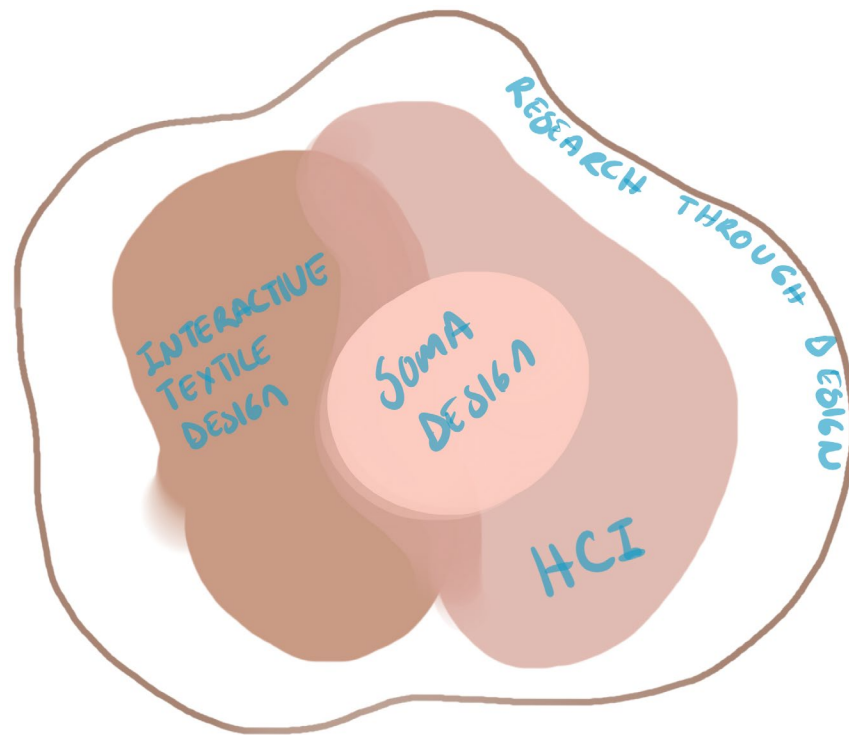


Figure 3. This dissertation adopts soma design that emerges within HCI and overlaps with interactive textile design. Illustration by Arife Dila Demir.

Based on somaesthetics (Shusterman, 1999), soma design aims to design somatic interactions that bring beauty to everyday life and extend human perception of the world and themselves (Höök, 2018). Emerging in the third wave of HCI, soma design is one of the design approaches that invite embodied thinking in design processes and value first-person lived experiences as an insightful resource for design use (Höök, 2018; Höök et al., 2018). In addition, designing movement-based interactions entails designers engaging with their somas and gaining bodily knowledge of moving and being moved (Hummels et al., 2007). In experiencing themselves in movement, designers discover and learn new aspects of their embodied existences by developing a first-person perspective. These discoveries may support meaningful ways of bodily being and sensory appreciation skills and the extensive study of first-person discoveries can inform the design outcomes successfully (Neustaedter & Sengers, 2012a; Núñez-Pacheco & Loke, 2020). On the other hand, soma design does not solely focus on the cultivation of the first-person experiences of the designer. Referring to autoethnography, it aims to cultivate the lived experiences of the users to inform the design process. Kristina Höök et al. (2018, p. 3) define the first-person perspective as an approach that “places the user’s lived experience at the core of the design process – the lived experience of moving and being moved become the main unifying activity during the

design process”. They also refer to the users’ lived experiences from first-person perspectives. In this research, I use the term ‘first-person perspective’ to refer to my own felt experiences and ‘second-person perspective’ for my understanding of the participants’ lived experiences. The first-person perspective indicates the application of our own bodily experiences as a resource in the design research process, whereas the second-person perspective refers to the exploration of others’ experiences through kinesthetic empathy that is our ability to feel the other moving and sensing bodies (Svanæs & Barkhuus, 2020). They draw a distinction between second and third-person perspective, which explores the experiences of others. They argue that “I-You relationships [second-person perspective] are characterised by being mutual, holistic, and without the objectification of one another, different from I-It relationships [second-person perspective], where the other is a means to an end” (Svanæs & Barkhuus, 2020, p. 3). In learning about the nuances of my felt experiences through a first-person perspective, I cultivate somatic insight that enables me to approach the participants’ lived experiences through kinesthetic empathy.

Accordingly, I adopt autoethnography to engage with the first and second-person accounts of pain experiences to inspire the design of soma extensions. In other words, in the making of artefacts for this dissertation, my pain and the participants’ pain become the main resource for understanding the somatic reflections of pain. Autoethnography focuses on developing detailed and evocative texts from a first-person viewpoint that bridges autobiographical accounts to others (Armitage, 2013). Respectively, the autoethnographic turn in design invites deep first-person insights to connect the personal to the social; it merges research and expressiveness. In autoethnographic writings, the author generates texts from which the reader can cultivate their meanings (Turner, 2013). In autoethnographic design, the main research outcomes are the artefacts through which the users can ascribe meanings and understandings. For instance, in using soma extensions, the bodies in pain can develop their perceptions in relation to their pain. Autoethnography locates the subjectivity of designers at the centre of the research; through examining themselves, designers work towards the unknown, which entails being open to the unfoldings of the self (Schouwenberg & Kaethler, 2021).

In this research, I start the inquiry through a close examination of my felt experience of pain, which helps me to develop a deeper insight into this phenomenon and informs me on how to better structure the participant study to cultivate others’ pain experiences. The self-examination process uncovers otherwise hidden dimensions of my pain and the participant's pain experiences, informing not only the study but also the people involved in the study by bringing them close to their somas. As mentioned above, evocative texts are produced for autoethnographic studies in the humanities and in autoethnographic design in addition to the texts. Designers generate expressive artefacts. In this dissertation, the primary outcome of the autoethnographic interrogations is the soma extensions and textual autoethnographic articulations of my research participants. This dissertation, therefore, comprises a collection of autoethnographic narratives of the bodies involved in the research and presents the soma extensions as tangible articulations of those narratives.

The process of creating autoethnographic texts and artefacts is an iterative process. Autoethnographic creations unfold in nonlinear processes where the text is re-created through a process of reflection and reflexivity in which all the bodies are involved in the writing process (Armitage, 2013). In this research, not only are the autoethnographic narratives and artefacts produced through an iterative process but the dissertation itself is also a result of a reflective and reflexive journey that is informed by the autoethnographic creations. Accordingly, in the creation of this dissertation, methodology, theory and making are in a constant flux of reflection, informing one another and influencing the ways of conducting the research leading to the research outcomes. Such an iterative process constantly revisits the previous steps, re-reads the theories, analyses the results, and adjusts the methods, making and theory according to

the reflections. In *The Reflective Practitioner*, Donald Schön (1984) reveals that unorthodox issues disable technical solutions and require experiential, intuitive practice. This experiential intuitive practice is referred to as tacit knowledge, in other words, know-how. In tacit knowing, the practitioner acts without thinking prior to her actions; the knowledge of what to do comes from her previous practice which provides an insight into how she handled the case. Tacit knowledge is not necessarily graspable for the practitioner, as when asked the practitioner may not answer how and why she performs certain actions during the research process. However, when reflecting on and in the actions, know-how becomes explicit, as Schön (1984, p. 61) refers “a practitioner’s reflection can serve as a corrective to overlearning. Through reflection, [s]he can surface and criticize the tacit understandings that have grown up around the repetitive experiences of specialised practice and can make new sense of the situations of uncertainty or uniqueness that [s]he may allow [her]self to experience”. Accordingly, this research is a reflexive inquiry where through reflecting on my actions I curate the next steps of my research as well as through reflecting on the actions I make necessary immediate alterations in the research process.

Finally, to examine the main research question, I conduct three case studies to explore the different sub-questions that emerge in the research process. The case study method enables the in-depth study of particular aspects of phenomena. Case studies extract specific connections between causes and effects rather than revealing the average effects of factors that cause effect (Given, 2008). Accordingly, I scrutinise the essential aspects of the phenomenon and put forward the main research question via case studies exploring the connections between pain and the body in the context of somaesthetic awareness.

1.1.1. Non-habitual Bodily Engagements as a Method for Cultivating Felt Experiences

Since this study adopts a soma design approach that uses first-person lived accounts as a creative site for thinking and making, it proposes various methods to cultivate first-person felt experiences for design use. Höök (2018) discusses disrupting habitual ways of moving as a method to notice how our bodily movements play a role in our emotions, perceptions and understandings. Höök suggests engaging with somatic practices – Feldenkrais, tai chi, yoga or dance – that break the habitual as a core principle to slow down and eventually disrupt the perpetual mundane bodily use. For instance, while slow walking, we can pay attention to each step and how each foot touches the floor, or while washing the dishes we can recognise the touch of the water, the materiality of the dishes, our body posture, etc. Breaking the habitual is based on the premise that, in engaging with the non-habitual bodily movements, we can generate somatic insight and facilitate somaesthetic awareness (Höök, 2018), providing new bodily perceptions (Bell et al., 2005). Engaging with the non-habitual first emerges in the arts as defamiliarisation by Victor Shklovsky, which aims to shift the usual perception and typical associations of objects (Crawford, 1984). Respectively, humans could change their perspective by performing unusual bodily movements to gain new perceptions and bodily understandings (Loke & Robertson, 2013). Paul Tennent et al. (2021) discuss defamiliarisation as a soma design trajectory that may guide the awareness of a person to the intended object by making a familiar situation strange.

As I wrote in the Introduction in the section titled *Personal Background*, being a certified yoga instructor and an improvised dance practitioner, I use these methods to break the habitual ways of living and being with pain and to be attuned to pain. In other words, I examine my pain in and through my moving body. Similarly, the participants of this study are invited to be aware of the felt qualities of their pain through moving. In doing so, I cultivate the nuances of this discomforting phenomenon that provides profound insight into the design of the soma extensions. The soma extensions aim to break our habitual experience of chronic pain to prompt new ways of living and being with it. To break the habitual soma extensions, I use movement-based and discomforting interactions. I explicate disturbing and pleasant aspects of

chronic pain in soma extensions; hence, the wearers can deliberately communicate with their pains in an unusual way developing new bodily perceptions of chronic pain and a somaesthetic awareness of it. “Human embodiment shapes how we are and can be in the world and our capacity of action within it” (Loke & Robertson, 2013, p. 7). Accordingly, by embodying the physical manifestation of chronic pain via the soma extension one can shape different ways of being and living with it.

1.2. Data Collection and Data Analysis Methods

In this section, I first explain the design research data collection methods that are used to cultivate the felt experiences that my participants and I experience. Following that, I illustrate the design research data analysis methods that are employed in the different case studies. This section aims to give an overview of these methods; an in-depth application of them is provided in the respective case study chapters.

1.2.1. Data Collection Methods

I use various data collection tools according to the needs of each case study to address the research questions and to inform the designing of the soma extension. To capture the complexity of the lived bodily experiences in each case visual and textual tools are combined to provide a rich understanding of chronic pain. Accordingly, in what follows, I present all the data collection tools that were employed in this dissertation.

Making: The making of soma extensions is a data collection method used in this study. The iterative making process provides data regarding the design possibilities of soma extensions, informing what qualities can be constituted by the artefacts. In other words, through ongoing testing of materials and techniques, I develop material knowledge regarding textiles and sound that can be employed to design soma extensions that facilitate somaesthetic awareness. Respectively, the designed artefacts of this dissertation do not solely contribute to the meta-level knowledge outcome, but they are also design contributions. The artefacts demonstrate how to translate intangible lived experiences of pain into tangible soma extensions. In addition, my textile designer background influences the design of the artefacts. How I choose the materials and techniques to create soma extensions intuitively arises from my previous experiences of material and form. Hence, the artefacts are composed of the felt experiences of the bodies involved in the research and my background as a designer.

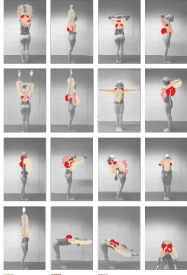
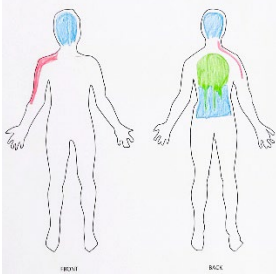
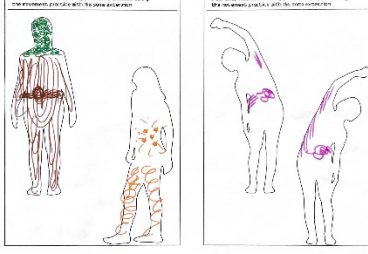
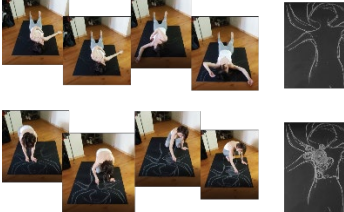
Kinesthetic Engagements: As discussed previously, somatic inquiries begin with kinesthetic engagements; that is, they start with experiencing oneself in and through moving, sensing and feeling. Kinesthetic engagements are ways of mining felt experiences regarding the concepts in question through defamiliarisation. In this dissertation, I illustrate two applications of kinesthetic engagements: 1) cultivating the felt sensations of being in pain, and 2) cultivating the felt sensations of interacting with soma extensions. The former is applied to understand the experience of pain to inspire the design of soma extensions conceptually and in terms of design decisions. The latter is applied to evaluate the influence of the soma extensions and to cultivate the experience of soma extensions to inform the design iterations. Kinesthetic engagements in different forms are applied in all the case studies of this dissertation.

Body Maps: Body maps (BM) are research tools for communicating somatic experiences that are generally applied in health research (Gastaldo et al., 2018). Denise Gastaldo et al. (2018) recognise body maps as art-based techniques that reflect people’s lives and their bodies visually. Claudia Núñez-Pacheco and Lian Loke (2016) discuss the value of body maps in the cultivation of the tacit dimension of bodily experiences and suggest that body maps can help to communicate thoughts, emotions and ideas, which are sometimes not easy to express via written or spoken language. In pain and discomfort health studies, BMs alter the medical practitioners’ understanding of their patients and the way they communicate with

them (Boudreau, 2018). They are regarded as a useful tool that provides information about the location of pain that helps researchers to uncover the relationship between the pain location and the severity and mechanisms of pain (Boudreau, 2018). Through body mapping, people can “reflect upon the connection of their minds, bodies, feelings, thoughts, experiences, and social interactions” (Skop, 2016, p. 31). In other words, BMs provide visual data of felt sensations reflecting hard-to-speak experiences. They may not be enough to communicate all the aspects of felt experiences; however, they facilitate conversations and work as a complementary tool to elicit felt experiences when combined with written or verbal methods, such as interviews or journal writings (Demir et al., 2022). In soma design, BM is employed to reflect somatic felt sensations, hard-to-speak embodied experiences and to capture complex emotions (Cochrane et al., 2022). As discussed by Karen Cochrane et al. (2022), BMs are generative tools that have five uses, including 1) to sample somatic experience, 2) foster heightened self-awareness and inner dialogue, 3) understand the dynamics, and evolving experience of the body over time, 4) identify patterns of bodily experience, and 5) transfer bodily experiences via experiential qualities into a physical design.

In this dissertation, BMs are employed in all three case studies, but in different forms (Table 1). I regard BMs as design research methods to elicit first and second-person experiences of chronic pain. As shown in Figure 7, in the first case study BMs are used as drawings on photographs of the moving body to: 1) sample somatic experiences of moving with the pain for design ideation, and 2) test the experiential qualities of the prototype. In the same case, a standardised, black-outlined body map is chosen for use with the participants. As this standard version of the body maps generally resembles the male body, to create genderless body maps, I distort the common BM outlines. In the second case study, black-outlined BMs are employed to elicit second-person experiences over the long term to reflect the dynamic evolving qualities of bodies in pain. Different from the first case study’s black-outlined BM template, in the second case, I draw the BM template according to the movement experiments that participants are asked to do. In doing so, I cultivate how each movement influences their bodily sensations, movements and perceptions. Finally, the third case study adopts a similar approach to the first case study for cultivating first-person experiences and uses BM as drawings on the still images of moving bodies. Accordingly, BMs are employed to elicit the felt experiences of both me and the participants to inspire design ideation, to provide insight into the felt aspects of chronic pain, and to highlight the felt qualities of the soma extensions. BMs are often associated with creativity, artistic expression, and the person’s drawing ability. For research purposes, this is not the case, yet participants may feel that they lack the ability to draw body maps. As researchers we need to emphasise the aim of the BM when working with participants. Finally, the reason for using black-outlined BMs with participants is due to the convenience of its application, photo drawing requires tools and previously prepared still images, standard BMs come in handy for second-person elicitation when movements happen on the spot or happen without the presence of the researcher.

Table 1. The different forms of BMs used in different case studies for cultivating first and second-person felt experiences of chronic pain and of using the soma extensions

BM on the photos of the moving images			
Standardised black-outlined BMs			
Real-Size BM			

Journal: A journal is a tool to record lived experiences in a text format and provide insights into the concepts that are examined. Journal writings include emotions, introspection and self-reflection; therefore, recording rich personal experiences from the inner lives of participants and researchers (Given, 2008). In this dissertation, the journal is used as a tool to capture first and second-person lived experiences. In the first case study, it is applied to capture my felt experience of moving with pain which then inspires the design of the first iteration of the soma extension. On the other hand, in the second case study, the journal is part of the cultural probe kit study where participants are asked to write about their experiences after each movement practice. I regard the journal as a door that opens onto the somatic life of people making what is intangible graspable for oneself and others.

Video Recordings: This dissertation works with/in/through/for moving bodies; hence, bodily movement explorations are an essential part of the design process. To capture the experiences of the moving bodies I use video recordings that offer the possibility to revisit past events providing rich embodied data of the felt experiences of moving. Video documentation reveals the hidden dimension of the felt experiences of moving and they provide vital details regarding nonverbal communication (Given, 2008). I adopt this method to capture the kinesthetic engagements that were performed to cultivate the lived experiences for

design use as well as to document the testing of the soma extensions, which is a whole-body performative experience.

Voice Recordings: Voice recordings are data collection tools that offer additional details of conversations by capturing elements of tonality and emphasis (Given, 2008). I apply voice recordings to document interviews and self-reporting sessions, which help me in the analysis of these verbal data.

Semi-Structured Interviews: The semi-structured interview is a data collection method where the researcher asks predetermined yet open-ended questions to the interviewee. Generally, the researcher prepares a guide in advance that may be specific or may include a list of topics to be covered (Given, 2008). I use semi-structured interviews in the first and second case studies to gain an in-depth understanding of the participants' bodily experiences. In the first case, I conduct two interviews, one before the study begins and one at the end of the study; the study is one and a half hours long and included the testing of the prototype (see Chapter 3). The first interview informs the participants' experience of pain in general and the second provides information on how the designed artefact influences their pain perception. Unlike the first case, I employ the interview method in the second case study after reading through the participants' journals and seeing their body map drawings as well as plasticine shapes (see Chapter 4). Therefore, I already collect some information regarding their felt experiences, and the interviews help me to gain a better understanding of their experiences in general and of their visual data.

Self-Reporting: The first case study is finalised by testing the second iteration of the soma extension on my body. I organise a similar testing structure as I do with the participants in the same study (see Chapter 3). Accordingly, I adopt semi-structured interviews in the form of self-reporting where I record my voice reporting on my lived experience before and after wearing the soma extension. Self-reporting enables me to document my lived experiences and reveals the felt sensations emerging from engaging with the soma extension.

Cultural Probe Kit: Cultural probes are a collection of small-scale objects that relate to a specific research question and context (Wallace et al., 2013). They are tools for acquiring inspirational data from the participants that may stimulate imagination (Gaver et al., 1999); hence, they are for design and understanding (Wallace et al., 2013). Cultural probes pose intriguing questions and collect responses through the creative engagement of the participants with the probes (Wallace et al., 2013). They intervene in the everyday life of the participants to elicit informative and incentive data about the part of their lives that is connected to the research questions. In this dissertation, I apply cultural probes to cultivate second-person experiences of chronic pain. This method is specifically used in the second case study where the aim was to cultivate a deeper insight into the people's experiences of chronic pain. Cultural probes can be used longer term, which enables participants to better engage with the probes generating richer and deeper data.

1.2.2. Data Analysis Methods

To conduct the three case studies, I applied three main analysis methods: 1) thematic analysis, 2) narrative inquiry, and 3) video analysis as a visual narrative inquiry. On many occasions, these three methods were utilised together to tackle the complex set of embodied data generated by the participants and me. An in-depth explanation of how these methods were employed in each case is illustrated in the respective case study chapters. Accordingly, in what follows I give a general overview of these three methods.

Thematic Analysis: Thematic analysis is a qualitative research data analysis method that categorises and reconstructs data, illustrating important concepts within the data set (Given, 2008). It provides the

patterns of an experience and highlights the experiences, thoughts, or behaviours across the data set (Braun & Clarke, 2019; Given, 2008). The product of thematic analysis is the themes which are the patterns (meanings) that emerged in the data set and informs the research question (Kiger & Varpio, 2020). In constructing the themes, Kiger and Varpio (2020) illustrate six steps including: 1) familiarising oneself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the report. In the construction of the themes, thematic analysis is also open to interpretation, and as it focuses on revealing the shared understandings of the experiences it is less suited for exploring unique meanings (Kiger & Varpio, 2020). In this dissertation, thematic analysis is applied to ascertain the patterns of lived experiences that inspire the creation of the soma extensions and provide conceptual design strategies to inform the design process. In the first case study, it is used to analyse my journal writings that are translated into the somatic experience map with the themes that emerge in the analysis (see Chapter 3), which then inspire the design of the first soma extension. In the second case study, the thematic analysis helps to illustrate participant experiences in using CPK to create design strategies regarding how to design more engaging soma extensions (see Chapter 4). Finally, in the third case study, thematic analysis is used to interpret the visual and textual documentation of my bodily movement exploration to mine the various themes of chronic pain to be applied in the design of the soma extension (see Chapter 5).

Narrative Inquiry: Narrative inquiry is the intimate study of people's unique experiences that happen over time in a given context; it is a way of understanding the particularities of lived experiences. Narrative inquiry invites researchers to be attentive to the participants' interactions and consider experiences as a narrative phenomenon (Given, 2008). Participation lies at the centre of narrative inquiry, where the research participants are involved in the interpretation and generation of the narratives. For instance, in writing participant stories, the active participation of the participants is necessary when I negotiate each entry with them before publication (Given, 2008). Similarly, in life, writing about illness, disabilities, and the vulnerability of the subjects has been discussed as they share their intimate bodily information (Couser, 2018). Accordingly, narrative inquiry constitutes relational ethics and encourages researchers to engage with ethical issues in their research processes (Given, 2008). I regard ethics as a necessary caring practice in working with bodily concepts, especially, bodily discomforting experiences. Narrative inquiry is applied in the second case study to extract the particularities of the participants' experiences of the cultural probe kit in relation to their chronic pain. In doing so, I illustrate the unique subjective experiences of the participants exemplifying how in using the same kit and practicing the same routine people might cultivate different somaesthetic awareness (see Chapter 4).

Video Analysis as Visual Narrative Inquiry: Similar to narrative inquiry, the researcher's first-person experiences shape the relational space with the participants in visual narrative inquiry. Visual narrative inquiry is a dynamic process of making meaning of the experiences; it builds stories as a way of thinking about the experiences (Given, 2008). Therefore, it is the study of the visual details of bodily interactions, revealing the hidden dimension of the felt experiences that is hard to verbalise, if not impossible. As this study focuses on designing with/for/through moving bodies in discomfort, I generate various visual data to capture the experiences of moving bodies, specifically videos. These videos are used to understand bodily interactions to inform the design.

CHAPTER 2

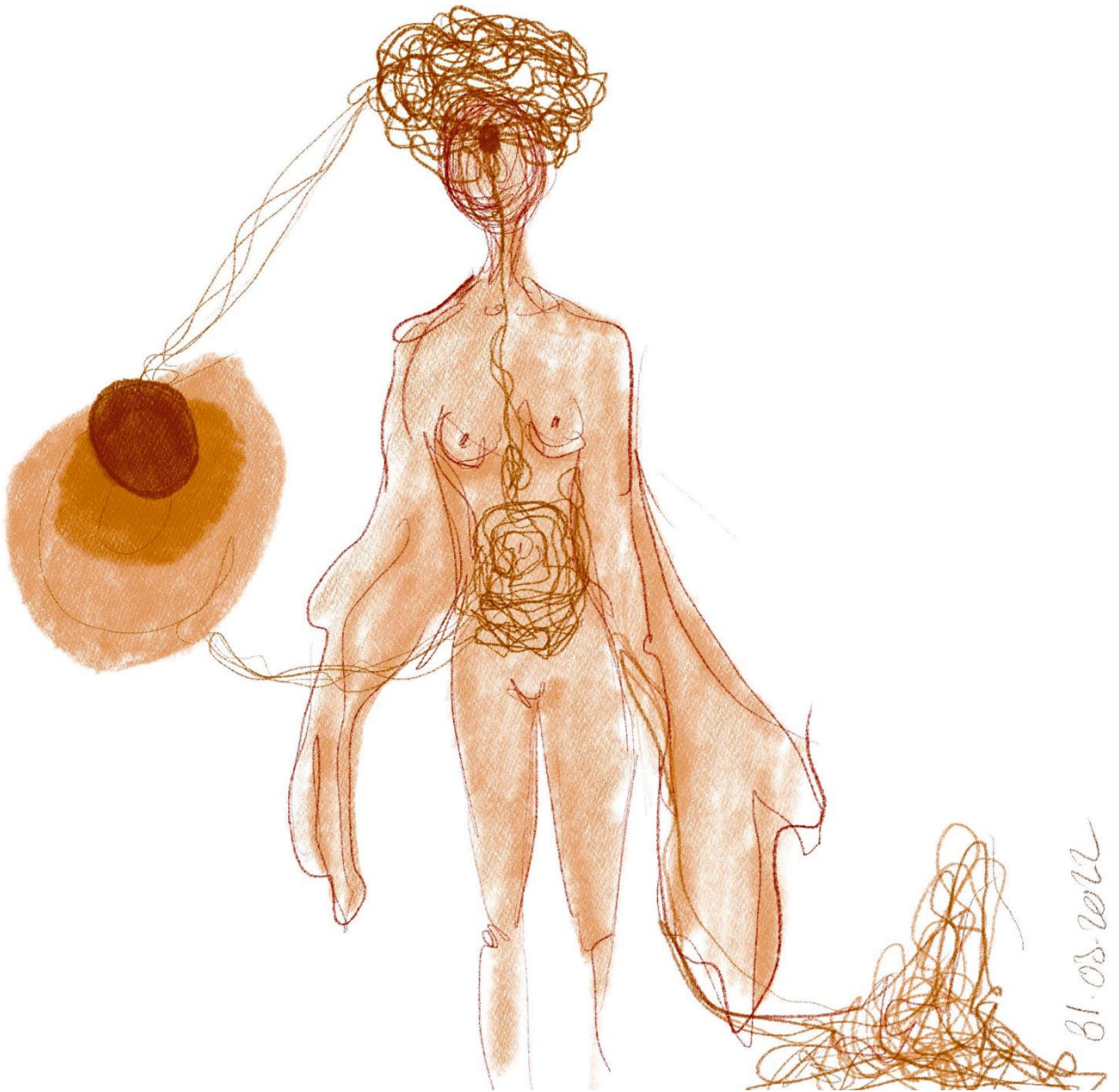


Illustration by Arife Dila Demir

2. THEORETICAL BACKGROUND: SOMAESTHETIC BECOMINGS

Diffraction/intra-action – cutting together-apart (one move) in the (re)configuring of spacetime-mattering; differencing/differing/differencing.

Diffraction is not a set pattern, but rather an iterative (re)configuring of patterns of differentiating-entangling.

(Barad, 2014, p. 168)

Correspondence, in this sense, is the process by which beings or things literally answer to one another over time, for example, in the exchange of letters or words in conversation, or of gifts, or indeed in holding hands.

(Ingold, 2017, p. 14)

In introducing what a diffractive approach might look like, Karin Murris and Vivienne Bozalek (2019) discuss that diffraction opposes binaries and that theory and practice are not binary oppositions; they propose to read theory with practice diffractively guided. When discussing diffraction, Karen Barad (2014) begins to explain re-turning “as in turning it over and over again”; she reflects that it is a process of iteratively intra-acting, re-diffracting in the creation of new temporalities. In this chapter, I introduce the theories that inform this dissertation; in doing so, I depict how theory and practice are entangled and inform each other in the development of my research. I show how each text helps me to develop an understanding of the previous texts I read and the artefacts I make; rather than focusing on their differences, I illustrate their entanglements. From each theory, each reading, I take different pieces to carry with me, I organise and re-organise those pieces, constantly making new meanings. As Kristina Andersen (2013, p. 17) reflects, “texts are like images, like scraps of color and texture...I carry them with me, take them out, rearrange them and reconsider them... changing meaning over time, coming into focus and fading back into incomprehension again...”.

Similarly, I carry the texts with me; I take them out for a walk, run with them, and constantly move with them. Sometimes I put them on a shelf then I revisit them. When I revisit them, they change their meanings; therefore, I and the artefacts I make change their meanings and take new shapes with them. Through the constant flux of reading, making and moving, I cultivate the different meanings of the notions of sense-making through movement, somaesthetics, and correspondence that I am working with. This is an ongoing process of engaging with theory and practice. Therefore, in this chapter, I present what these theories do to my thinking and making. How I approach theories and the making processes is inspired by the diffractive methodology, which is used in the making of new temporalities (Barad, 2014). This methodology opposes holding one theory, perspective, or text as foundational (Murris & Bozalek, 2019) and allows one to be attentive to the influence of the differences and what could emerge from the unexpected (Andersen, 2013). In other words, the diffractive approach enables constant becomings of the concepts, notions, artefacts, and humans rather than apportioning them fixed meanings. Accordingly, when I introduce the theories, concepts, and notions I work with in this dissertation, I will be presenting my temporal stand on those issues. They will keep evolving and becoming anew as I further my engagement with them even after the completion of this dissertation.

My interest in movement and what movement does to my thinking, living, making and perception leads me to readings of phenomenology (Gallagher, 1986; Merleau-Ponty, 2002; Sheets-Johnstone, 1979). Through phenomenology, I engage with embodied cognition (Shapiro, 2014; Wilson, 2002), which provides an insight into how cognition is tied to bodily experiences. With my interest in movement and somatic movement practices (i.e., yoga and dance) I meet with somaesthetics (Shusterman, 1999, 2006) that enmeshes with phenomenological thinking through incorporating somatic practices. All these three theories, phenomenology, embodied cognition and somaesthetics, oppose the mind-body dichotomy and argue that humans experience the world in/through/with their bodies, which is the basis of perception and cognition. These three entangled theories form the philosophical grounding of this dissertation, which will be presented in this chapter. Informed by these theories, this dissertation explores the possibilities of augmenting somaesthetic awareness via interactive wearable artefacts, namely the soma extensions, in the context of chronic pain. It aims to promote somaesthetic awareness in the existence of discomforting events, thus mediating discomforting interactions through the soma extensions. In doing this research, through reading and making, my perception of somaesthetics is transformed from being solely the literal awareness of body parts or visceral bodily awareness to cultivating self-care, self-ethics, and self-aesthetics. In addition to these theories, Tim Ingold's (2016) notion of correspondence forms my current understanding of interaction. He describes correspondence as the literal act of responding and answering of things and beings to one another. Accordingly, the notion of interaction in this dissertation evolves from being regarded as the interplay of two things or beings upon one another to being regarded as mutual communication, the mutual becoming of things and beings as they entangle with one another. Therefore, in the first case study, I focus on the influence of the soma extension upon the wearer, whereas in the second and third case study, I explore the corresponding interaction of the soma extension and the wearers and that of their together becomings.

This dissertation opposes the dichotomies of mind-body and theory-practice. The design approach of this research, namely, soma design, which is developed based on the philosophy of somaesthetics, entangles with the ideals of phenomenology and embodied cognition. In addition, as I conduct autoethnographic research, reading, thinking, making and moving are also strongly tied to my bodily existence. I start to explore the research questions through my body in chronic pain, continue with the other bodies in chronic pain, and then return to my body. In this exploration, I adopt the abovementioned theories that alter my perception of pain, my thinking, and my making of the soma extensions, as a result. Andersen (2017, p. 17) writes, “[o]ften the objects I make can be seen as diagrams of the relationships between one notion and another”. Similarly, the artefacts I designed illustrate the relations between philosophical notions, between texts, and between my body and other bodies with chronic pain.

In what follows, I illustrate the meanings of somaesthetic awareness in the context of chronic pain through the lens of phenomenology and embodied cognition. Specifically, I first examine the sense-making process in movement, then argue for body consciousness as the basis of somaesthetic appreciation, and finally, discuss the somaesthetics of discomfort.

2.1. From Movement to Sense-Making

Our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive, it breathes life into and sustains it inwardly and with it forms a system.

(Merleau-Ponty, 2002, p. 235)

Every being and thing becomes one with movement and continues with movement. As for humans, once we were all an embryo moving inside a womb pulsating subtly, connected to the world with an umbilical cord. As we grew into a fetus through developing limbs, our subtle movements became relatively more vivid. Approximately eight months later we moved ourselves into a new world outside of the womb. This world constitutes animated and nonanimated beings and things and we could acknowledge their existence through our audio-visual-tactile-olfactory-gustatory-kinesthetic senses. To communicate with this world, we made sounds, gestures, and used our whole bodily movements through which we experienced ourselves, the things, and the beings around us. We come into this world through our moving and sensing bodies, and until we rest in our eternal sleep we will exist in the world in/through/with our bodies.

In the *Phenomenology of Perception*, Maurice Merleau-Ponty (2002, p. 94) writes, “[t]he body is the vehicle of being in the world, and having a body is, for a living creature, to be intervolved in a definite environment, to identify oneself with certain projects and be continually committed to them”. In the phenomenological account, the creation of the episteme is based on sensory bodily experiences. As Merleau-Ponty (2002, p. 252) has put it: “I have senses and they give me access to the world”. Sensory experience, therefore, is how humans communicate with the world. In doing so, phenomenology opposes the Cartesian dichotomy of the mind-body separation that disregards the body’s role in meaning-making processes. The moving and sensing body, which is the subjective body, is referred to as the lived body in phenomenology. The lived body is both mind and body, both subject and object; it is the sensory body through which we experience the world and ourselves (Gallagher, 1986). In other words, humans make meanings regarding the world and themselves through the lived body.

Shaun Gallagher (1986, p. 144) defines the knowledge of the lived body as pre-conscious knowledge, saying that “this implicit or tacit knowledge, which is not an objectifying consciousness, is also not a reflective consciousness”. The episteme of the lived body is pre-reflective. What is given to us in experience first enters in a pre-reflective state in which the lived body interacts with the world. Things and beings become available to our consciousness, become cogito, when we reflect upon our experiences. Merleau-Ponty’s phenomenology aims to obtain a direct description of things that appear to us as they are; that is, to examine the world that exists in a pre-reflective state. In this dissertation, I move beyond the pre-reflective state for two reasons: 1) without reflection we cannot explicitly grasp and communicate the bodily experiences, and 2) without reflection we cannot be consciously involved (if necessary) in the bodily experiences for new becomings.

I am inspired by Merleau-Ponty’s philosophy of taking the body as the primary site for meaning generation and the role of perception in human experience that forms the basis of meanings. I am interested in humans’ knowing both in pre-reflective and reflective states. Richard Shusterman discusses that reflection can improve the richness and pleasures of bodily experiences and it enables changes in habits, behaviours and perceptions. Simply through consciously engaging with bodily experiences, humans can alter how they are and how they experience the world and themselves. To be involved in human bodily experiences in a reflective state, I engage with Shusterman’s philosophy of somaesthetics that entangles with phenomenological thinking. Shusterman (2006, 2008) offers a pragmatist philosophical system called somaesthetics, which comprises both theory and practice of the lived bodily experiences.

Somaesthetics is “the critical study and meliorative cultivation of how we experience and use the living body (or soma) as a site of sensory appreciation (aesthesia) and creative self-fashioning” (Shusterman, 2008, p. 1). In the account of somaesthetics, the word ‘soma’ is similar to the lived body in the phenomenological account; soma is considered a tool for being in and experiencing the world. Accordingly, in this dissertation, soma refers to the sentient, lived, experiential aspects of human beings

which are more-than-flesh-and-bones or a physical corpus. In founding somaesthetics, Shusterman employs his bodily knowledge developed through somatic practices that he has engaged in, such as Feldenkrais, Alexander Technique and Zen practice. The premise of somaesthetics is that, through improving their somatic knowledge, humans can improve their way of being and living in the world, and by improving their somatic knowledge, they can engage with somatic practices (Shusterman, 2006 & 2008).

According to somaesthetics, humans go back to bodily movement via somatic practices and seek the philosophical understanding of bodily consciousness not merely in thinking without the body but in thinking in/through/with the body. Through phenomenology, I discuss that through our bodies we experience the world, make meanings, and develop understandings. Through somaesthetics, I discuss engaging with somatic practices that enable humans to experience and perceive the world and themselves differently. I regard movement as the primary site for cognition. In the embodied cognition discourse, this is called the perception-action loop, where cognition is rooted in having a body with sensorimotor capacities (Shapiro, 2019, 2014; Wilson, 2002). Francisco J. Varela et al. (1993, p. 173) write about the enactive approach in cognitive science that consists of two points: 1) “perception consists in perceptually guided action”, and 2) “cognitive structures emerge from the recurrent sensorimotor patterns that enable action to be perceptually guided”.

The enactive approach in cognitive science suggests that how humans perceive the world depends on their actions, which are informed and guided by perception. Hence, the actions of how humans dress, care for themselves and for others, develop aesthetic appreciations, and regard abstract notions (e.g. ethics) alter their perception, and the altered perception in turn influences these actions. Informed by the perception-action loop, I explore how humans can develop new meanings and actions by engaging in non-habitual bodily movements, discomfort, and moving strangely in the context of chronic pain. Viktor Shklovsky coined the term defamiliarisation as an art technique to present familiar things in an unusual and strange way to gain new perspectives (Crawford, 1984). This thinking of engaging with the non-habitual and breaking habits for new understandings is also employed in bodily interaction design (Höök, 2010; Loke & Robertson, 2013; Wilde, 2011). Through embracing aspects of discomfort, I design unfamiliar movement-based interactions aiming to cultivate somaesthetic awareness concerning chronic pain.

Thus far, I discuss that being in the world for humans is an embodied practice and it is not possible to separate human perception and cognition from the body. Respectively, the key notions of this dissertation are: 1) moving to design with and for, 2) engaging with discomfort, 3) engaging with the strange, and 4) cultivating somaesthetic awareness. The exploration of these notions requires rigorous engagement and articulation of bodies that are in constant movement flux. According to Maxine Sheets-Johnstone (2010), humans dynamically move and attend; they discover themselves in movements as animate organisms. Animateness becomes a definitive of aliveness in which we develop ‘I cans’ through making sense of the world that we live in which is where cognition begins (Sheets-Johnstone, 2011). Accordingly, in this dissertation, I develop various ‘I cans’ that shape my understanding of somaesthetics and apply them to the designing of my artefacts. In return, these artefacts may become triggers for developing “I cans” for bodies living with chronic pain.

Autoethnographic Interlude: *Everything started with movement, I pushed myself and was pushed to a new world through contractions from my first home – the womb. I do not have any memory of this time whether I was consciously reflecting upon my bodily experiences or not. For sure, I was in a constant movement flux; I just do not remember it nor think about it. So, I will say that I started to move, and be conscious about my movements in 2013 when I started practicing yoga. Since then, I*

am interested in how moving shapes us and how we shape our movements, and I explore the endless possibilities of constant transformation in movement.

So far, I have discussed how everything started with movement and how we make sense of and through movement via the lenses of phenomenology, somaesthetics, and embodied cognition. All these theoretical stances reflect how I approach myself, my body, and my pain, which forms the context of this dissertation, to craft human-computer-interaction and research. In other words, in this dissertation, I regard humans as having a sensory body, in and through which they experience and make meanings of themselves and the world. In considering movement as the source of meaning-making, this dissertation explores the possibilities of developing somaesthetic awareness and new perspectives on our embodied selves through engaging with non-habitual movements. I employ various somatic practices such as yoga, dance, and craft practices as research methods. My research starts in and through movement and it becomes movement itself. In the next section, I will present the notion of somaesthetic awareness which is the core concept of this dissertation.

2.2. Cultivating Somaesthetic Awareness

In the previous section, I illustrated how humans as embodied beings are involved in meaning-making processes through their bodies and explained the constant influence that perception and action have upon each other. Respectively, I design movement-based bodily interactions to influence people's perceptions and actions in the context of chronic pain aiming to promote somaesthetic awareness. I regard the action of 'promoting' as creating a space for people where they can cultivate their understanding of somaesthetics through engaging with non-habitual bodily experiences. To specify what is considered somaesthetic awareness in this dissertation, I will first explain Shusterman's understanding of somaesthetics and my interpretations of it.

According to Shusterman (2006), somaesthetics aims to improve our knowledge of the body by extending the meaning, understanding, effectiveness, and beauty of our movements and the world. In doing so, it suggests that humans can find ways of living better lives. It is defined as a meliorative practice that focuses on enhancing "the use of our bodily instrument in perception, cognition, action, aesthetic expression and ethical self-fashioning" (Shusterman, 2006, p. 13). Improving somatic knowledge constitutes the very core of somaesthetics, as Shusterman highlights, it is a meliorative practice. In other words, it is a practice that focuses on becoming better to live better lives. This dissertation does not regard somaesthetic awareness as reaching an ultimate and objective state of being better. Rather, I regard 'becoming better' as a subjective notion for which individuals need to attain their meanings of what better means. In addition, rather than using the word 'being better' I use 'becoming' to refer to somaesthetic awareness, and I advocate that heightened bodily and environmental awareness would aid people to experience new becomings.

'...our very being is a flux of becoming something else...'

(Shusterman, 2006, p. 9)

Body awareness is discussed as sharpening the consciousness of bodily feelings and actions; it is a reflective somatic process that guides us to better self-use (Shusterman, 2008). The self-use here is not merely referring to the functional matters of the body as flesh but it includes a perceptive awareness of somatic existences that will improve human capacities for pleasure (Shusterman, 1999). As Shusterman

points out, being aware of the body is a reflective process. A person can be aware of painful stimulation in their body which is a type of awareness in recognising and being conscious of bodily sensations. However, this does not necessarily mean that this person is understanding and corresponding to their pain. Accordingly, I will draw two types of body awareness: 1) passive consciousness of bodily sensations, and 2) active consciousness of bodily sensations. The former is merely recognising the bodily sensations without reflection, without active engagement with them, whereas the latter is a reflective process where the person corresponds with the bodily sensations. In this dissertation, the latter is the type of body consciousness that I aim for and find necessary for somaesthetic awareness.

Somaesthetic awareness requires the explicit articulation of bodily phenomena, which happen before reflection and become available to the consciousness of the person. However, it does not mean that the pre-reflective experiences are not important; to be able to reflect, we first need to engage phenomena at the pre-reflective level. Shusterman (2008) introduces the four levels of consciousness: 1) motor intentionality; 2) conscious perception without explicit awareness (pre-reflective); 3) conscious and explicit awareness of perception (somaesthetic perception); and 4) reflective somatic perception with explicit awareness (somaesthetic self-consciousness or reflection). The first level ‘motor intentionality’ is where we unconsciously perceive our bodies. For instance, if our breathing is disrupted during sleep, we unconsciously adjust how we sleep without waking up. At the second level, we might reach backward with our arms to grasp something that we know is there and can reach through our arms, but we are not conscious that we know all these explicitly; rather, we just perform the action. At the third level, we are explicitly aware of how long our arm is, and how much it can rotate while we are reaching backward. At the fourth level, we reach a higher reflective level where we are also explicitly aware of how our self-consciousness influences our actions and related feelings. When aiming for somaesthetic awareness via interactive wearables, I aim to aid the wearer to engage with second-level experiences at the third and fourth levels.

As I mentioned before, in this dissertation I cultivated different meanings of somaesthetics which altered the making of the soma extensions. I first regard somaesthetic awareness as being conscious of the physical bodily chronic pain that may influence the living practices of a person with pain. Then as the study progresses, I regard somaesthetic awareness as cultivating self-care, self-ethics, and self-aesthetic understanding. Hence, the understanding of somaesthetics expands from merely developing a consciousness of the physical body to a reflective caring practice. Shusterman (2006 p. 12) writes “care of the self is improved when keener somatic awareness advises us of problems and remedies before the onset of pain’s damage”. On the other hand, somaesthetic awareness is not a fixed point, it is an ongoing process, constantly changing and becoming anew. It is something that humans are required to engage consciously and reflectively to experience new becomings. In what follows, I discuss the somaesthetic awareness of bodily events that cause discomfort, specifically chronic pain.

2.3. Somaesthetics of Discomfort

Bodily experiences result from both external and internal stimulations. Implicit bodily experiences influence our meaning-making processes and performance of being and living in the world. They can change how we perceive ourselves and can distort body ownership, as seen when discomforting sensations alter the body perception negatively. Shusterman (2006 p. 3) notes “often I also perceive my body as something that I have rather than am: something I must drag out of bed to do what I wish to do; something I must command to perform what I will but that often fails in performance; something that includes heavy limbs, rolls of fat, a sometimes aching back, and a too often unshaven, tired-looking face, all of which I recognise as mine but do not identify as who I really am”. In other words, the experience of

discomfort might cause the emergence of the feeling that the body is something like a hindrance that a person has.

I define bodily discomforts as chronic bodily conditions such as chronic pain, depression, fibromyalgia, etc. These discomforts alienate us by changing our bodily capabilities which influence how we perceive an act (Shusterman, 2019); that is, discomforting experiences force involuntary changes in our lives by disrupting our habitual ways of living. In *On Being Ill*, Woolf (2021) touches upon agonising experiences that shatter the illusion of the world where we go to work, school, do sports, travel, and other places by forcing us to stay in bed and leaving us in torment. Mark Tschaepé (2021) defines the changes that are brought forth by discomfort as “the shift from harmony with the world one inhabits to disharmony” (p. 2). Accordingly, bodily discomforts are events that interrupt our habitual way of living in conformity and tranquillity. When experiencing discomfort, we turn our awareness to this agonising phenomenon that becomes the source of our existence and how we perceive ourselves. Shusterman (2008) discusses that despite the intense pleasures, body awareness tightly focuses on painful experiences; hence, embodiment constitutes a discomforting vulnerability. Discomfort demands attention to the state of being, whereas comforting experiences may remain unnoticed in our conscious experience (Tschaepé, 2021), regardless of the vividness of pleasurable experiences, our body awareness is firmly fixated on painful events (Shusterman, 2019).

Bodily discomforts claim our attention, yet this does not necessarily mean that we will respond to these bodily sensations. One can also choose to ignore, suppress, or become stagnant and passive in the face of agonising events. However, when we choose to actively engage in and be attuned to our discomforting experiences, we can transform them and find better ways to live with them. Shusterman situates pain in a melioristic framework discussing that pain can act as a catalyst to enhance our experience in relation to it. By somaesthetically engaging with our discomforts, we can improve our conscious awareness and be perceptive to what may cause or trigger discomfort and take actions to avoid or minimise it (Shusterman, 2019). Through cultivating the somaesthetic awareness of discomfort, we can train our diseased bodies to experience discomfort (Tschaepé, 2021); that is, through somaesthetic awareness, diseased bodies can find new ways of being and living with discomfort. In this dissertation, I consider the somaesthetics of bodily discomfort as heightening our conscious and reflective awareness of discomforting phenomena and finding other ways of living and being with the discomfort. Bruce I. Kodish (2004) utilises the notion of a “more alert state of awareness” to refer to where people are open to new experiences and consider what they can do rather than perceiving the experiences as phenomena that happen to them. This state is where new becomings might emerge. Shusterman (2008) reveals that attended consciousness of painful events needs to be examined before they can be properly transformed. In other words, through reflectively engaging with bodily events that cause discomfort, humans can alter their bodily experiences that may lead to new becomings.

On the other hand, somaesthetics of discomfort starts with the acceptance of disturbing experiences; only then can one start the transformative journey with discomfort. When bodily discomforts are chronic, their removal is challenging if not impossible. Acknowledging the difficulty of the total removal of discomfort, I draw my definition of the somaesthetics of discomfort as enhancing one situation with the agonising phenomenon. Similarly, comfort is considered a state of being that is not inevitably focused on the elimination of discomfort but on improving the state of being (Tschaepé, 2021). As Shusterman (2019) writes, in living with pain we learn to accept our frailties even as we search for a remedy. Accordingly, acceptance of painful events does not exclude the quest for treatment but avoids denial and empowers the person to find new ways of being. Reflecting on his pain journey, Richard B. Hovey (2018) uses “the gift of chronic pain” to refer to the healing of this phenomenon that focuses on becoming new with it. He

writes that through reflective engagement with his pain, he was able to re-engage with the world and himself and that reflection is a vital tool for exploring the gift of pain.

To engage with our discomfort reflectively, we need time and space to be attuned to our bodily sensations, to cultivate bodily insights, and to communicate with the discomfort. Discomfort moves us from an objective time where all the daily tasks are happening to a subjective time where we experience our bodily sensations. *Kairos* is a Greek term referring to a subjective time in which people can settle into their bodily experiences and reflect, by contrast, *Chronos* indicates the objective time that is measurable using the clock (Brough, 2001). *Kairos* is the “moment of opportunity and hopefulness” and “a meditation about how ... life becomes better and still evolving” (Hovey et al., 2018, p. 99). It invites reflective conversations with our bodies to create new narratives with our diseased and eased selves. We can settle into our bodily experiences in *Kairos* to understand and correspond with them. Finally, as discussed in the previous section, I consider somaesthetics as being aware of, understanding, and corresponding with bodily sensations in order to cultivate self-caring practices. The somaesthetics of discomfort therefore entails the creation of *Kairos* for such dialogical conversations with our diseased bodies to become anew.

CHAPTER 3



Photograph by Mehmet Can Boysan

3. CASE STUDY 1: SQUEAKY/PAIN

Take time to learn the subtle flows and tones inside your body.

(Haines, 2015, p. 27)

Having chronic pain does not necessarily mean that the experiencing person discerns nuanced felt aspects of pain. Rather, pain as an implicit bodily event has subtle qualities that are only available for heightened conscious awareness. By attending to bodily experiences, one can cultivate those nuances. As a subjective experience, the same kinds of pain might be manifested differently in different bodies mediating distinctive qualities for each individual. In this chapter, I will present my first case study that explores the ways of cultivating and using pain in the process of designing soma extensions, and investigating the possibilities of facilitating somaesthetic awareness through explicated interactions of chronic pain. Case Study 1 discussed that a person can transform her pain experience through paying attention to pain and actively engaging with it. It considered that designing with/for/through chronic pain entails designers acquiring otherwise unnoticed subtle qualities of pain to inform the design process. To gain in-depth insights into the felt experience of chronic pain, this case study cultivated felt experiences via first and second-person explorations discerning diverse qualities of pain. To do this, I first explored lived aspects of pain by delving into first-person exploration. Following that, I harvested second-person reflections of other people who experience pain. The case study investigated the possibilities of promoting the somaesthetic awareness of pain by transferring those qualities into the design of a soma extension. Since chronic pain may cause fear of movement and the feeling of losing control over the body, this case study considered transforming the pain experience as gaining control of the body and regaining self-confidence in relation to bodily movements. In this regard, as a soma extension, *Squeaky/Pain* emerged as a physical manifestation of pain mimicking its qualities through sound mediating kinesthetic interactions. Through the sound-motion interaction, it provided a venue for people to communicate with the explicated manifestation of their pain to develop a somaesthetic awareness of it.

3.1. Aims of the First Case Study

The aim of the dissertation was to cultivate the felt aspects of the pain experience and to transfer them into the design of soma extensions that were movement-based interactive wearable textiles mediating the pain experience through different sensory mediums. In doing so, it explored the possibilities of soma extensions to facilitate the somaesthetic awareness of chronic pain which identified new ways of living and being with pain. I suggested that the body moves with pain to connect with, understand, communicate to, and be aware of the pain. Accordingly, to examine how soma extensions might facilitate the somaesthetic awareness of chronic pain, I needed to understand how to cultivate the felt aspects of the pain experience to use them as design materials. Therefore, in the first case study, I asked: *how may the chronic pain experience inform the designing of soma extensions?* To explore this sub-research question, I first cultivated my chronic upper body pain experience to gain a first-person understanding of the felt qualities of pain. I then translated the revealed aspects of my pain to the design of the first iteration of *Squeaky/Pain*. Later, to be informed by the second-person perspective experience of pain, I conducted a participant study testing the soma extension with three people who experience chronic pain and created the second iteration of *Squeaky/Pain* that was then tested on my body. Through this case study I discovered ways of cultivating first and second-person pain experiences and using pain as a design material. In addition, I acquired insights into the capabilities of the soma extensions to facilitate

somaesthetic awareness that is later explored in depth through the second and third case studies. In what follows, I will unpack the process of designing *Squeaky/Pain* and present the analysis and preliminary results.

Interlude: Designer's Autoethnographic Reflections on Pain

My pain started almost two years ago [Spring 2019]. Back then I was working in a textile design studio and at the same time finalising my master's project, which took almost three months to weave. When working with your hands and spending an infinite amount of time sitting with bad posture in front of a computer and a loom, your body cannot remain silent. Bodies always find their ways to communicate with us, we just need to learn [perhaps remember] how to listen to them. So, what was unavoidable happened, since I did not respond to the minor calls of my body, it went into an alarm state. This was the time when I felt that something was going wrong. From that moment, I started to wake up with a disturbing pain in my right shoulder spreading to the neck and sometimes to the left shoulder. I remember that I felt the quality of my life decrease, it felt like my body was second-hand; like I was living in a body that was used and worn out.

It is interesting how I detached myself from my body and internalised the feeling of 'I have a body' rather than 'I am the body'. This happened when I started to feel helpless regarding my pain; being helpless invited me to alienate myself from my body. I remember that I often felt that I have no control over the body that I am living in, and I must adjust my life according to this organic machine which is never compromised. For a while, I received massages to alleviate my pain which helped me to spend a few days in good condition till the pain became disturbing again. Meanwhile, I was practicing yoga. Well, I have practiced yoga regularly since 2013 and I am a certified yoga instructor as well. When my pain started, naturally it effected my practice as well. Due to the pain, I was not able to perform the postures that were once easy for me to practice. Now I was feeling pain when practicing many things, and so, I needed to adjust my practice accordingly. It is very disturbing to observe that your body is taking a step back and now you need to re-learn the things that were once possible for you. At one point, I also became too anxious about hurting myself, so it prevented me from engaging in challenging postures which then destroyed my motivation to move at all. Fortunately, I did not stop moving but I was not enjoying it either.

When you have a daily physical practice and when this practice is known to people to help with their chronic pain conditions, everything becomes even more frustrating to you. The reason is that because you think you do everything right, you take care of yourself, yet it is not enough to protect you from chronic pain. So, what do you do when this happens? I, of course, tried to adjust myself according to this new phenomenon that arose within my body (though I was not motivated at all!). Gradually, I learnt to move with my pain; both to alleviate it and to enhance my skill in my yoga practice. So, I sort of liberated myself from the idea that I may hurt myself if I challenge the capacities of my body. Today, I still have this pain problem, but at least I understand that by moving consciously, I can help myself to relieve and extend my physical capabilities. (Perhaps it is necessary to say that still today there are times when my pain experience dominates my thoughts and I manage it less successfully.)

*For me accepting the pain also took an awfully long time, as I was thinking that I was doing everything right, it should not happen to me. So, for a long while, I thought that this was going to end. Well, it is not ending, just getting 'better' and I learn to cope with it. I started to accept the situation later when I started to work on *Squeaky/Pain*. With this study, I realised much change has happened regarding how I perceive my pain, and how I deal with it in everyday life and my movement practices. Accepting the pain was the beginning of everything [I assume] because only*

then did I stop fighting with it and started listening to it. This helped me to improve my yoga practice again. Still today I feel the limitations and from time to time I feel frustrated, but I learn to move accordingly to be able to advance my movement practice. I guess for me I started to 'better' cope with the pain and 'enhance' my everyday life experience with it. Here I feel the urge to repeat that meaning of 'better' life and 'enhance' everyday life is a subjective matter, it is on different levels for different individuals. And the meanings can be changed over time, over the practice of inner awareness.

3.2. Design Process

This section portrays the three-phase design process that applies first and second-person perspectives in tandem. Adopting the soma design approach, the first phase of the design process started with a first-person somatic inquiry of me through a close examination of the studied phenomenon, pain. This phase of the study helped to produce visuals and ideas for the soma extension as informed by my daily experience of pain and the disturbances caused by it. Höök et al. (2018, p. 3) define the first-person perspective as an approach that “places the user’s *lived experience* at the core of the design process – the lived experience of moving and being moved become the main unifying activity during the design process”. They advocate that gaining insight into the first-person somatic experience provides a better understanding of the lived qualities of the body for the designer who wishes to design for bodily engagements. On the other hand, it has been discussed that combining second-person perspectives with the insight gained from the first-person perspective would inspire new realisations and a comprehensive understanding of the studied phenomena (Neustaedter & Sengers, 2012b). Accordingly, I conducted a participant study in the second phase of the study aiming to be informed by the felt experience of other people with chronic pain. I utilised the prototype to cultivate the felt experience of people with chronic pain which then informed the second design iteration of the prototype. The second prototype was then tested on me in the third phase. In what follows, I will provide an in-depth explanation of the design process which was unfolded in three phases.

3.2.1. First Phase: Designer’s First-Person Somatic Pain Exploration

The first phase began with a reflexive inquiry into the lived experience of my pain through an autoethnographic method inspired by soma design theory. Reflexive inquiry in autoethnographic studies refers to the involvement of the researcher’s whole bodily experiences, senses, feelings, emotions, etc. (Given, 2008). I conducted a reflexive self-inquiry with, in, and through my explicit and implicit bodily movements. I investigated my implicit bodily reactions to my pain experience, such as emotions, thoughts, and ideas that arose or were influenced by the pain experience. In addition, I explored the explicit physical movements that I perform to alleviate the pain or to show my discomfort due to pain. Being a yoga instructor enables me to prepare a yoga sequence (Figure 4) that helps me to alleviate my pain and keep my body moving despite the pain. More specifically, I was experiencing upper back pain located on my right shoulder which was occasionally spreading to the neck and the left shoulder. I practiced this yoga sequence daily for three weeks by focusing on my lived bodily experience to understand the ways to communicate with my body in pain. I video-recorded the first session of my yoga movement experience to have the visuals of the sequence; later these visuals were used to map the highlights of my three-week somatic exploration. During this exploration, I kept a journal (Figures 5 & 6) where I wrote about my felt experience immediately after each movement practice. Later, the experiment journal helped me to deconstruct my subjective experience to produce ideas for the design of a soma extension. Upon completion of the three weeks of somatic movement experience, I created a somatic

experience map (Figure 7) that visualises the significant features of my felt experience which was documented in the journal.



**Figure 4. Yoga movement sequence which I practiced every day for three weeks.
Photography by Mehmet Can Boysan.**

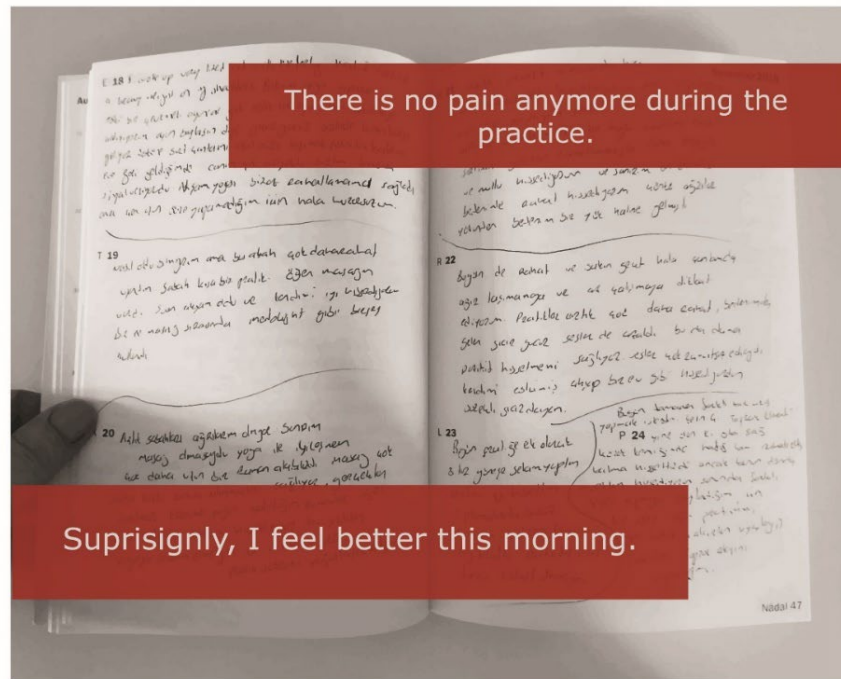


Figure 5. Extractions from my journal. Illustration by Arife Dila Demir

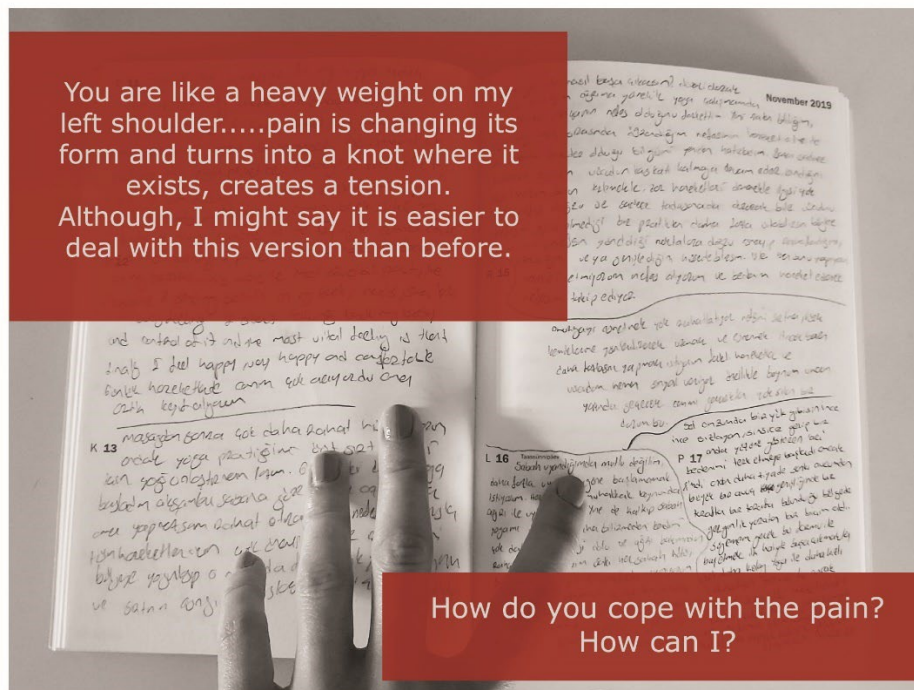


Figure 6. Extractions from my journal. Illustration by Arife Dila Demir

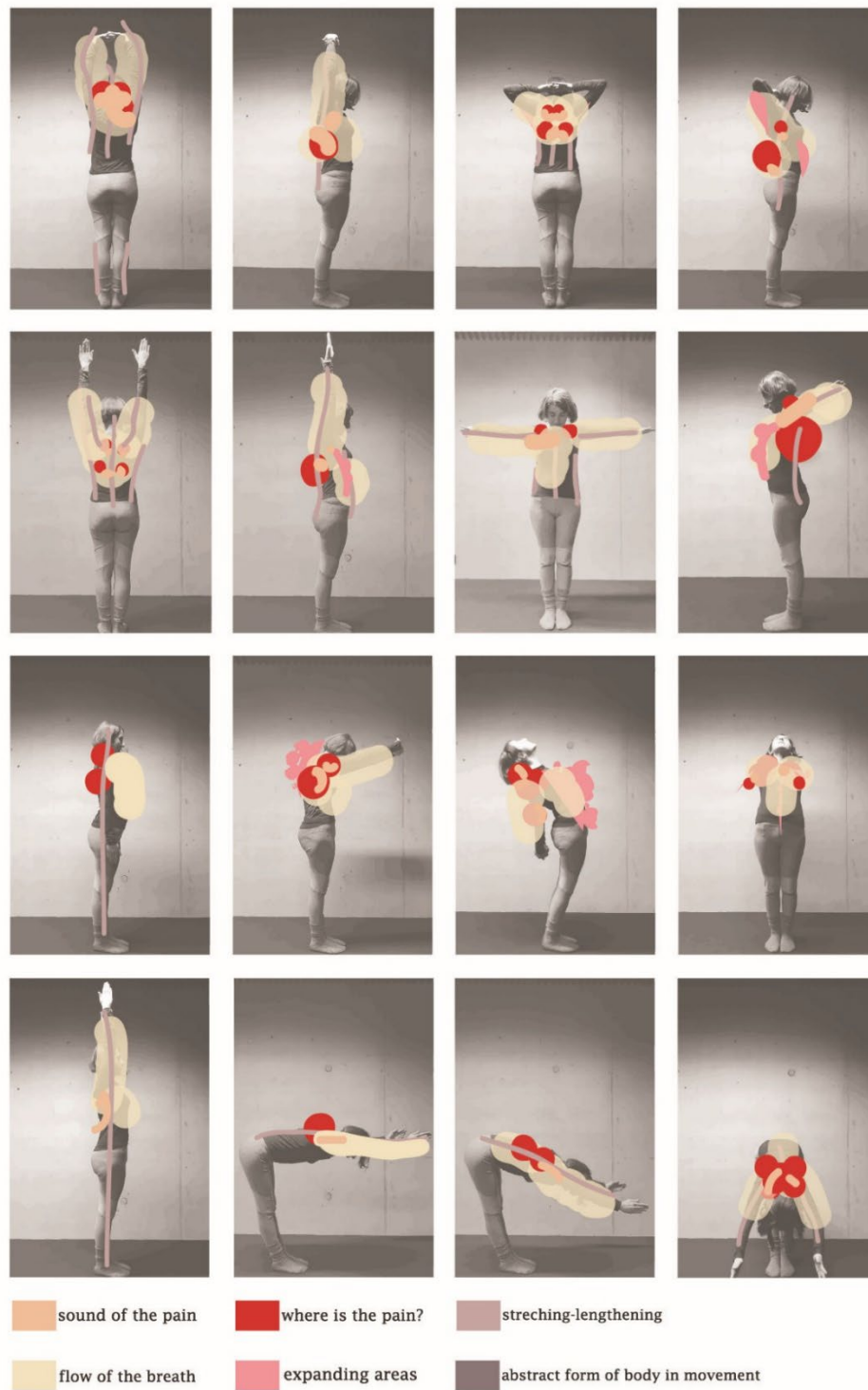


Figure 7. Somatic experience map. Illustration by Arife Dila Demir

Practice is much easier now, the sounds that were coming from my body have decreased and this makes me feel more positive. The sounds were extremely disturbing; I was feeling like an old wooden house that squeaks all the time.

(Extraction from experiment journal, 22 November 2019)

The somatic experience map includes the repeated aspects of my lived experience of pain during the movement experiment. For instance, the sound of the pain was repeated several times in my journal. During the movement experiment, sounds were coming from my body as I moved, and these sounds were like squeaky wood which made me feel like I was an old wooden house. As I moved in each pose, particular parts of my body were stretching, and I was feeling the expansion via breathing and the flowy movement of the breath in my body. Finally, the location of the pain was an important part of my experience. As I stated in my journal, I was feeling the magnitude of the pain changing from day-to-day but there was still a specific point or location where I felt the pain.

You are like a heavy weight on my left shoulder which aches on the sly. The insidiously emerging pain now leaving my body; it is taking another form that is bigger than my fist and creating tension where it exists. I should say it is easier to handle this version. This new version is relaxing faster with yoga; however, when in first moves it does not fall behind but reminds itself. Like it does not want to be forgotten or it reminds me to take care of my body.

(Extraction from experiment journal, 22 November 2019)

All these repeated aspects cultivated by the reflexive inquiry of my lived experience of pain helped me to develop design ideas for the soma extension, which then led me to the prototyping process. As this PhD research focuses on augmenting somaesthetic awareness in the existence of bodily disturbances, in the first design iteration I focused on translating the disturbing qualities of my pain experience into the design of a soma extension mimicking the pain experience when the wearer is engaged with it through bodily movements. On the other hand, as I mentioned in the section *Interlude: Designer's Autoethnographic Reflections on Pain*, I often felt pain controlling my body and developed an anxiety about moving, thinking that I might injure myself. When I acknowledged my pain and accepted it (even though I do not enjoy nor fully make peace with it), I realised that it was much easier to move.

In psychological pain management methods, Acceptance-Commitment Therapy (ACT) highlights the importance of accepting the existence of the disturbing phenomenon. Acceptance in ACT refers to “the ability to assume an open stance towards the pain experience and [it] is offered as an alternative to fruitless attempts to control or avoid pain” (Trompetter et al. 2015, p. 51). McCracken et al. (2013, p. 1399) state that ACT “focuses on behavior change and on any manipulatable influences that can be applied in changing behavior, incorporating influences based on emotional experiences, thoughts, beliefs, and social context”. The idea of accepting the pain became an essential part of developing design ideas for the soma extension. Through the soma extension explicating the pain experience, I aimed to create an experience where the body in pain was required to acknowledge the pain, listen to it, and then explore ways of communicating with it by moving with it. I advocate that such experiences might augment sensory bodily awareness by influencing the perception of pain.

In other words, I utilised the disturbing features of my pain experience as a design material to design an interactive soma extension. I focused on embracing *painfulness*, rather than pleasurable sensory experiences that directly aim to alleviate or suppress the pain. This approach aimed to provide an experience where people can achieve alleviation through gaining somaesthetic awareness, by carefully communicating with the sensory body. Accordingly, *Squeaky/Pain* was designed as an interactive

wearable textile that offered sound-motion interaction as well as a tactile experience. The sound of squeaky wood was chosen as a main sensory stimulus to mimic my experience of pain. The inspiration for the squeaky wood sound emerged from my journal writings. The soma extension generates sound after being worn for 30 seconds and the whole interaction lasts for seven minutes. When the sound starts, turning it off is not possible. Yet it is possible to keep the volume of the sound at a certain level by moving slowly. With this designed interaction, the soma extension created a way to accept the pain and move in the presence of it. For this interaction, a movement sensor (MPU-6050), Arduino, and music shield were embedded in the soma extension, and headphones were used to provide a more personalised soundscape for the sound feedback. The soma extension aimed to promote defamiliarisation for augmenting sensory bodily awareness by slowing down the movements of the wearer. In making the familiar strange, it is possible to influence body perception and augment sensory awareness (Loke & Robertson, 2013; Tennent et al., 2021).

While designing the interactive aspect of the soma extension, I engaged with form and material explorations to design the tangible soma extension. First, I started by drawing a body map (Figure 8), which was the actual size of my body. Akin to the somatic experience map, which was a body map as well, I used this actual-size body map as a tool to explore two-dimensional expressions of my pain experience for visual autoethnography. As shown in Figure 5, the body map focuses on the painful areas of my body; inspired by the map, I extracted the two-dimensional pattern of the wearable soma extension. Later, I expressed my pain through various textile materials and stitching techniques (Figure 9). I investigated the material qualities of my pain by engaging with rough paper yarn through weaving (Figure 9A). Following this, inspired by the forms that emerged in my actual-size body map, I explored three-dimensional organic forms using visible red stitches to connect the materials that represented the infinite and sickening feeling of pain. These material engagements helped me to develop the visual and tactile qualities of the soma extension, resulting in the final form of the first iteration of *Squeaky/Pain* (Figure 10). This final form of the first iteration was based on my actual-size body map drawing, covering the areas affected by pain. After different material explorations, I decided to build the soma extension using neutral colours akin to my body aiming to represent pain through varying textures, materials, and continuous red stitches. For instance, I needle felted the arm part creating spreading circular textures that represent warm sensations emerging from my pain. In addition, I used the three-dimensional worm-like material placed on the lower back part to embody the disgusting agony of pain.

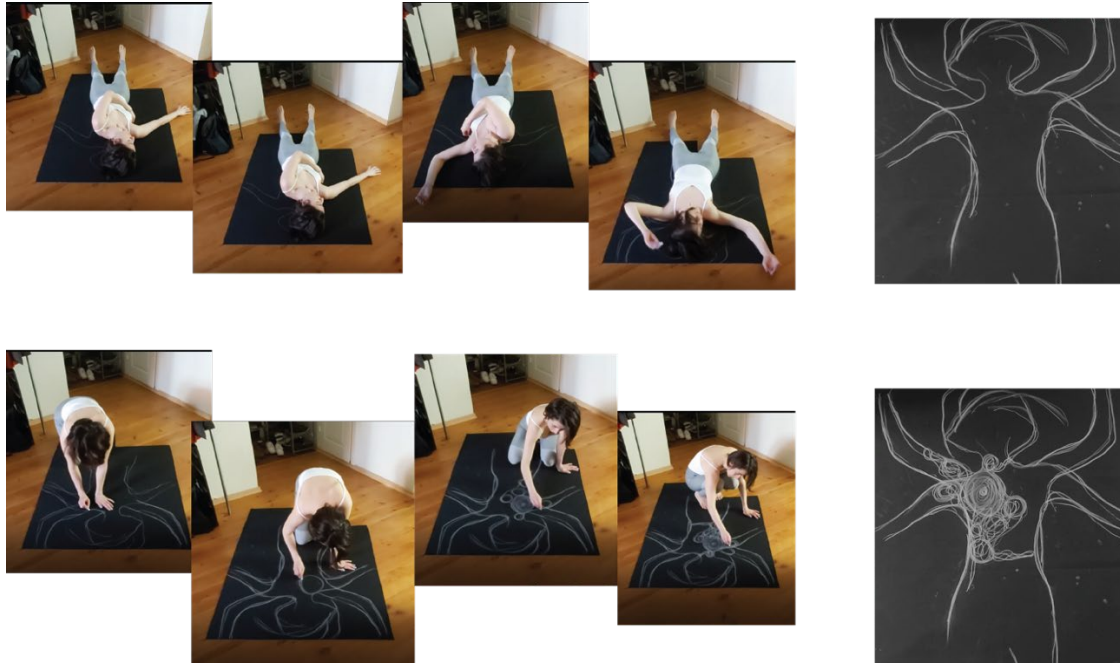


Figure 8. Real-size body map that informs the two-dimensional pattern of the wearable soma extension. Photographs by Arife Dila Demir



Figure 9. Different material engagements to express my pain experience. The first row consists of woven textiles with paper and hemp. The second row consists of a combination of various materials and textiles with stitching. Photographs by Arife Dila Demir

Finally, in the early stages of the first phase, by moving and observing my body in motion I attempted to explore the tacit dimensions of my felt experience. Then, I converted the tacit dimensions into tangible

information via written reflections in the form of a journal and still images of the moving body in the form of a somatic experience map. Later, by engaging with different materials, I exposed what was unrevealed through written and visual autoethnographic documentation. Therefore, the three-dimensional material samples were the expressions of my pain experience that illustrated what I was not able to articulate in spoken or written language but can be understood via experience. The first phase of the study was finalised upon the completion of the first iteration of the soma extension. Throughout the first design iteration, I tested the artefact on my body. In this testing and making process, I did not aim to capture my distinct experience with the soma extension. Rather, my focus was on the technical functionality and usability of the artefact in terms of its interaction and how it fits on the body. The testing of this first iteration was conducted via participant study which is described in the next section.



Figure 10. First prototype of *Squeaky/Pain*. Photograph by Kadri Tiganik

3.2.2. Second Phase: Participant Study as an Inquiry into the Somatic Pain Experience of Others

I conducted a participant study to explore the effects of *Squeaky/Pain* on other people with chronic pain and to be informed by their lived experiences with pain for the second design iteration. The study involved three participants, selected from responses to an open call sent via email channels in the universities in Tallinn. People responding to the call first filled out an online questionnaire to provide information about their pain history to evaluate whether they are eligible for the study. The selection criteria were that the participant should have chronic pain (pain existing for more than six months) and musculoskeletal pain mainly located on the upper part of the body. I conducted a one-and-a-half-hour one-on-one session with the three chosen participants. The session consisted of four stages: 1) in-depth

semi-structured interviews supported by body drawing charts; 2) guided movement and breathing; 3) non-guided movement with the soma extension; and 4) in-depth semi-structured interviews supported by body drawing charts. The interviews were audio-recorded and the third stage of ‘moving with the soma extension’ was video-recorded. The first stage provided information about the participants’ pain history and bodily perception of their pain experiences. The second stage aimed to be a warm-up movement practice before testing the prototype and to bring the participant’s focus to the body. As the design researcher of the soma extension, I guided the participants on how to move their bodies and perform breathing techniques. In the third stage, the soma extension was introduced to the participants, and they were given seven minutes to freely move in the study space. Following that, final in-depth interviews were conducted to collect information about the participant’s experience with *Squeaky/Pain* and its influence on their bodily experience.

The first two participants who were involved in the study on the same day at different times were guided through the same structure. As mentioned above, the second stage was about guiding participants to move (performing movements for the upper body by standing on both feet) and to breathe following my verbal instructions. Observing these participants revealed that the activity in the second stage affected how they moved in the third stage with the soma extension. As they were guided to be more static in the second stage, they mimicked the same idea in the third stage which prevented them from exploring available movements in their bodies. Another reason was that, during the second stage, they moved alone through my verbal guidance which created a situation where people needed to move in front of a stranger which made them hesitate to do so. For the third participant, I decided to make changes in the second stage to break the ice between the participant and me (the researcher), and to create a more relaxing environment where I could be silly with the participant. During the second stage, not only did I give a verbal guide to Participant 3, but I also moved with her. In addition, the motion sensor embedded in the soma extension on the upper arm for the first two participants, was moved closer to the spine for the third participant to facilitate rich movement explorations. Except for the changes in the second stage and the location of the motion sensor, the rest of the study was applied using the same structure as initially planned. Table 2 illustrates the pain history of the three participants. The information provided in Table 2 was collected via an online questionnaire and during the first in-depth semi-structured interview. ‘Duration’ and ‘Type of Pain’ information were gathered from the online questionnaire whereas the ‘Exercise Routine’ and ‘Feeling of Lack of Control due to Pain’ data were cultivated from the first in-depth interview. Therefore, the first two columns reflect the direct answers of the participants whereas the last two columns are from the notes I took during the interview.

Table 2 Information about the participants’ painful history.

PARTICIPANTS	DURATION	TYPE OF PAIN	EXERCISE ROUTINE	FEELING OF LACK OF CONTROL DUE TO PAIN
P1	‘since I was 18–19’	‘Migraine, cervical pain’	does not have a regular exercise routine (even though it has been suggested by the doctor)	Sometimes she is in control but when pain is strong and lasts for a long time then feels like the pain is in charge.

P2	'20 years'	'Depending on the activity in general muscle pain on the lower back, shoulder blades, hamstrings, inner feet'	has a daily exercise routine	Due to his long history of pain, he feels a lack of control rarely as he learns how to live with it.
P3	'[It] started since I was in teenage years, slowly got more severe'	'Lower back pain and pain in hips spreading to the legs'	tries to maintain a regular exercise routine	It depends on the degree of the pain experienced.

As discussed, this case study focuses on two aspects of facilitating somaesthetic awareness: 1) gaining control of the bodies that are agitated by the pain, and 2) facilitating inward focus on the implicit bodily experiences. The need to investigate the first aspect arose from the experience of people with chronic pain who often felt that they lose control of their bodies due to the pain that disrupts their everyday flow. The investigation of the second aspect arose as a necessity for somaesthetic awareness; to be aware of the sensory bodily experiences, it is essential to be able to focus and listen to the body, the soma. Accordingly, during the participant study, I investigated the influence of these aspects on the participants. These two aspects have the pre-requisite of mimicking the pain experience for the participant; therefore, whether the artefact resonated with the participants' pain experiences or not was first explored. The following quotes portray the participant's responses to whether their engagement with the soma extension was akin to their pain experience.

Louder sound [is] what I feel, what I feel inside. [It is] like my migraine and cervical pain. (P1, Interview 2)

Where it [the soma extension] touches locally on my body there was a feeling of pulling, I identify it with the pain experience. (P2, Interview 2)

Sounds [were] like squeaky trees and it was like [the feeling of] being stuck, like your joints are cracking. It was like [my] body is talking to me. [...] I [was] curious about the sound. It symbolises stiffness like pain. (P3, Interview 2)

Squeaky/Pain was designed as a tangible expression of my pain experience, and due to its sensory features, it succeeded in resonating with other people's pain experiences. The above statements showed that tactile and audible properties of the soma extension heavily influenced the participants' bodily perception and mimicked their pain experience. The participants perceived their bodies with, in, and through *Squeaky/Pain* via its sensory qualities. For each participant, the sensory qualities of the soma extension created different experiences. For instance, P1 and P2 stated that they felt restricted on the upper left side of their bodies (where the soma extension touches their body). P1 and P3 associated the tactile experience of *Squeaky/Pain* with positive feelings, but P1's experience was mostly focused on the lower parts of the soma extension.

On the upper left side, I felt restricted, I did not want to move that part of my body too much. But the lower parts were very soft and gentle, felt very nice. (P1, Interview 2)

I felt that it was tight, it was kind of restricting the movements. [...] The sound was incredibly unpleasant and like it was depressing; so, I wanted to walk toward to window to see outside, to be opened up. (P2, Interview 2)

[...] like a warm layer of my. (P3, Interview 2)

On the other hand, the feeling of restriction was one of the sensory aspects of the soma extension that mimics the pain experience of P1 and P2. The intensified feeling of restriction became an obstacle to the exploration of various bodily movements even for P3, who did not feel restricted but felt unsure about the flexibility of the soma extension. She stated, 'I was unaware of its flexibility, so, it stops me a little bit, otherwise I would bend more.' This informed the next design iteration and highlighted the need to create a soma extension that can be worn by bodies without the exaggerated feeling of restriction to encourage the wearer to move freely.

Based on the two aspects of soma aesthetics for evaluating the participant study, the soma extension is required to mimic the pain experience. Such mimicking of the pain experience became possible because of the influences of the soma extension's sensory qualities on the participant's body perception. For instance, the soma extension created a tightness and pulling feeling for P2, who correlated these feelings to his experience which then also influenced his body perception and how he navigated with his body. Ana Tajadura-Jiménez et al. (2020) discuss that body perception is not a fixed notion but a continuously changing phenomenon. This view suggests that, through constant sensory bodily interactions, people can construct new perceptions of themselves.

The first aspect of facilitating somaesthetic awareness was to augment the gaining sense of control over the pain. To promote the sense of control, I aimed to create a mutual communication between the wearer and the soma extension that symbolises the pain. Facilitating mutual interaction between pain and the body can encourage people to move with their pain promoting self-confidence. Robert Kugelmann (2003) mentions that pain is not a conscious choice. Rather, it occurs despite our desires. In this sense, what is important is to take control of the body over this undesired painful experience. When participants are asked directly whether they feel that the soma extension was controlling their bodies or that the interaction between the soma extension and their bodies was mutual, their answers indicated that none of them felt that *Squeaky/Pain* was controlling them.

It was more like a mutual relationship. I felt more in control when the sound was less loud and when it was louder, I was paying more attention to it and it was in control. (P1, Interview 2)

Because it is tight, it is a little bit restrictive in terms of movement; however, overall, I did not feel that it was controlling my body. (P2, Interview 2)

I did not feel like it was controlling my body, it was a mutual interaction. (P3, Interview 2)

Despite the tactile and audible disturbances, the soma extension augmented the feeling of mutual interaction based on body movements which were aimed to prompt the sense of gaining control over the body. The next aspect explored regarding somaesthetic awareness was the ability of *Squeaky/Pain* to facilitate an inward focus, guiding the awareness to implicit bodily experiences. The interaction with the soma extension required slow and estranged movements in order to keep the volume of the disturbing sound down. Through this interaction, I aimed to guide the attention of the wearer to their movements and implicit bodily experiences through the body movements. In that sense, the sound was the main element as a movement facilitator. How *Squeaky/Pain* works was explained to the participants in the last stage of the study, meaning that they did not know how it was designed to work while moving with it. For P1 and P2, thinking about how the soma extension works often created a distraction as they were not sure why the sound was generated.

[...] I wanted the sound [to] stay in a less loud[er] [level] but I did not understand that it was connected to my movements. (P1, Interview 2)

I focused on the extension and the sound to understanding the working principles.

(P2, Interview 2)

In addition, P1 and P2 reflected that the sound feedback loop was not well synchronised with the movement of the wearer, which can also cause a disconnect from the body movements. Despite this, P1 was still able to focus on her bodily experiences.

[...] some parts I felt relaxed and tr[ie]d[y] to concentrate on [my] breathing. Sometimes the feeling was natural and comfortable. [The] tension on [my] shoulder was going down but sometimes it was going up. (P1, Interview 2)

Contrary to the experience of P1 and P2 with the soma extension, for P3 *Squeaky/Pain* guided her focus on her bodily experiences and bodily movements. As she reflected, the interaction with the soma extension became a reminder of how to be sensible with her body. By reminding her of the pain experience, the soma extension guided P3 to focus on the body movements.

I try to understand how the sound was responding, this creates different patterns of movement. [......] even if you know that you need to move slowly sometimes you don't, so the sound brings attention to this point. (P3, Interview 2)

[...] like my body is talking to me – a reminder of movement. [...] I notice minor movements.

(P3, Interview 2)

It works more on the positive side as a reminder of pain, the denseness and stiffness of it. It creates [an] urge for movement. When I have pain very intensely, I feel very stiff. And this experience took away the attention from the pain and carried it to the movement. (P3, Interview 2)

Regarding movement, *Squeaky/Pain* facilitates different patterns of movement for each participant as it facilitated different levels of focus on movement. P1 and P2 were more static in their movements. They chose to stay in the same positions rather than explore different movements. They mostly chose to explore minor movements, which were often directed to engage with the extension tacitly and/or visually in order to understand and communicate with it. These patterns of movement reflected that the interaction was not clear to them, and they needed to create a tactile and visual relationship with it. On the contrary, P3 focused on the movement-based relationship between the soma extension and her body and explored various whole-body movements. As explained in section 4.2. *Design Process*, two alterations were made for the participant study of P3 following reflections on the participation of P1 and P2. The alterations included the placement of the motion sensor and the dynamic 'guided movement-breathing' stage through my physical participation. The findings of the study indicate that these changes were effective for P3 in terms of promoting the exploration of whole-body movements.

While conducting the interviews to cultivate the felt experience of the participants, I utilised body maps to reveal the tacit dimensions of the felt experiences, which may remain hidden when using writing or speech-based tools. To understand whether the soma extension makes any difference in their body perception in relation to pain, the participants were asked to draw body maps in Interview 1 (before they experienced the soma extension) and in Interview 2 (after they experienced the soma extension). Table 3 demonstrates the changes in the participants' bodily perceptions regarding pain through the drawings of their bodily experiences.

Table 3. Body map drawings of the participants during Interview 1 and Interview 2

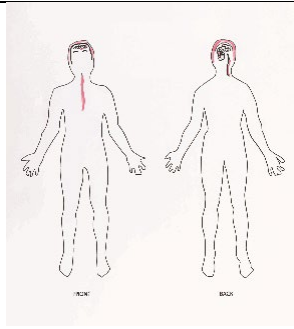
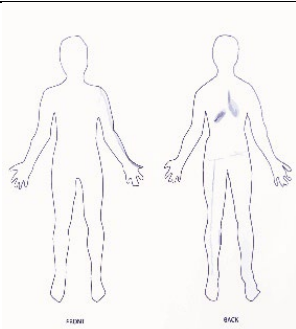
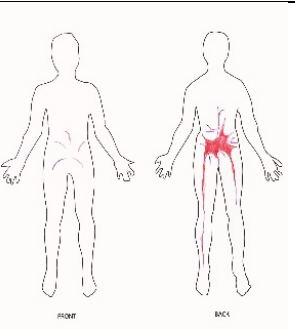
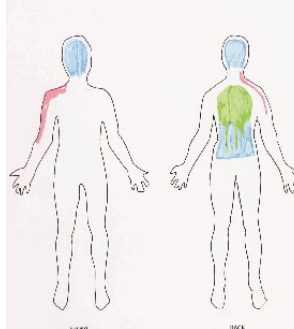
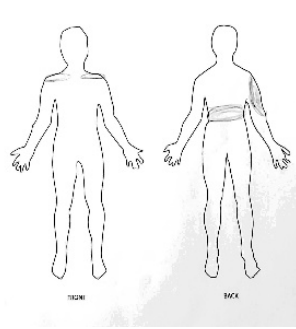
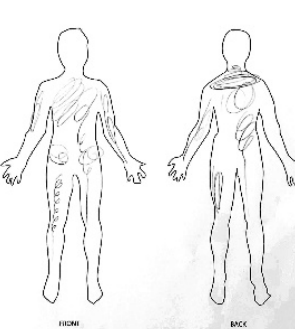
BODY DRAWINGS	PARTICIPANT 1	PARTICIPANT 2	PARTICIPANT 3
Body Drawing 1/ Before experiencing the soma extension/ Participants are asked to draw their bodily experience when pain is active			
Body Drawing 2/ After experiencing the soma extension/ Participants are asked to draw their bodily experience after engaging with <i>Squeaky/Pain</i>			

Table 2 indicates that the tactile feeling of the soma extension markedly influenced P1 and P2. They both performed their drawings by focusing on the body parts where the soma extension touched their bodies. After moving with the soma extension, P3's bodily experience was a continuous flow throughout her body. In relation to this, during Interview 2, P3 revealed that "I first moved with [my] upper body but then my legs wanted attention, then I started to move [my] legs". In general, while P1 and P2 mostly focused on the soma extension, P3 focused on whole bodily feelings, which was an introspective experience for her. In addition to the interviews and body map drawings, I analysed the video recordings of the participants to extract the meanings of their engagement with the soma extension that otherwise may remain hidden. The blue lines on the still images captured from the video recordings in Figure 11 specifically highlighted variations in the participants' upper body movements regarding their engagement with the soma extension. This analysis provided insights into the affordances of the soma extension in terms of bodily engagements and inward focus. For instance, P1's attention was sometimes distracted by the appealing tactile and visual qualities of the artefact; rather than focusing on different kinesthetic interactions, she was trying to get in touch with *Squeaky/Pain* (Figure 11A). Yet, from time to time she was still able to focus on her movements. Similarly, P2's attention was also taken by the visual and tactile qualities of the artefact; however, this became an obstacle for him to focus on his bodily movements (Figure 11B). Rather than outwardly attempting to engage with the tactility or visibility of the artefact, P3 focused on how the touch of the artefact was influencing her soma and explored different movement possibilities that emerged when wearing the soma extension (Figure 11C).

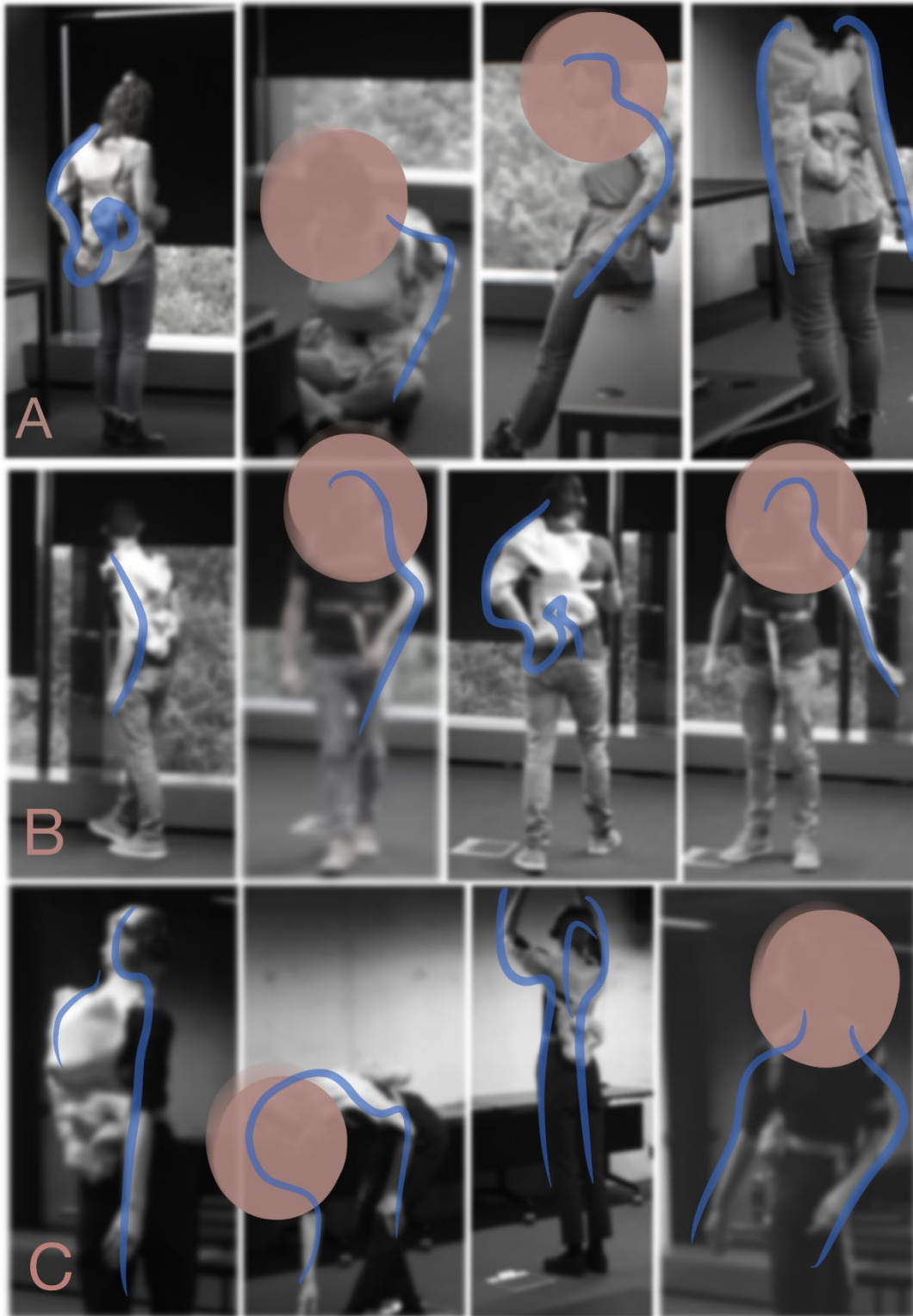


Figure 11. The visuals emphasise the kinesthetic engagement of the participants with *Squeaky/Pain*. Illustration by Arife Dila Demir

The idea of promoting somaesthetic awareness through unpleasurable, disturbing interactions requires more in-depth investigation and the participant study opened new rooms for exploration in that context. Finally, the participant study suggested the idea of incorporating feedback about what was pleasurable in addition to what was disturbing. Regarding the sound feedback, which consists of sounds of creaking wood, P1 and P2 stated that in some parts they heard the sound of a beach. P1 stated that she felt like she did not have any pain anymore and it is time for recovery. Even though this was not intended, it informed the future developments of the soma extension regarding the use of pleasant sound feedback to evoke positive connotations of the bodily feelings of pain, which may in turn support the idea of pain being alleviated when the body moves.

3.2.3. Third Phase: Returning to the Designer's First-Person Somatic Pain Exploration

The participant study demonstrated that *Squeaky/Pain* resonated with people's pain experience by mimicking its disturbing qualities and promoted the feeling of gaining control of the body in pain by creating a mutual interaction with the wearer. The second phase showed that the design of the soma extension requires enhancements to better guide the wearer to focus inward. The participant study revealed two aspects to improve the inward focus: 1) enhancing the synchronisation of the sound feedback, and 2) incorporating positive along with the disturbing sound feedback. In the first phase, I focused on understanding and translating my pain experience into the design of a soma extension by examining pain as a bodily discomfort. Yet, the second phase revealed that the alleviation of the pain represented by the pleasant sound is also a part of the pain experience, which can be applied to the disturbing qualities of pain. These aspects formed the objectives of the third phase and became the focus of the second design iteration of the soma extension.

In this, by aiming to enhance the capabilities of *Squeaky/Pain* to *better guide the inward focus*, I did not mean to design an artefact that might create the same influence on all wearers. In this study, the subjectivity of bodily experiences and their uniqueness are acknowledged. On the other hand, the first objective of the second iteration arose as a technical requirement, whereas the latter arose as a concept to enrich bodily interaction by providing different sound feedback aiming to evoke different bodily realisations. Several researchers have studied the influence of interactive sound feedback on human perception and movement. For example, Tajadura-Jiménez et al. (2014) discuss how different kinds of sound feedback influences human touch behaviours and material perception. In addition, Roberto Bresin et al. (2010) explore how various sound feedback as the expressive sonification of footsteps influence walking. Therefore, incorporating pleasant sound feedback in *Squeaky/Pain* created a complete interaction with pain, from agony to relaxation. In so doing, it augmented different bodily realisations regarding pain towards somaesthetic awareness.

The second iteration of *Squeaky/Pain* was tested on me to verify the effect of the improvements. It is worth noting here that the initial plan was to conduct a second participant study for the second test with the new artefact. However, the test could not be carried out due to restrictions arising from Covid-19. This limitation brought the design case back to the design researcher's body to test in a similar setting to the participant study. I followed the same four stages applied to the participant study: 1) in-depth semi-structured interviews, 2) guided movement and breathing, 3) moving with the soma extension, and 4) further in-depth semi-structured interviews.

Before the testing phase, the second design iteration of *Squeaky/Pain* considered the lessons learnt from the participant study. The re-making process of the soma extension first focused on the placement and form of the soma extension. The first iteration covered a bigger surface area on the body which was

extracted from the actual-size body map of me (Figure 5) that reflects the pain in my body. Regarding the location of the soma extension, the participant study indicated that the tactile feedback (where the soma extension touches the body) is an essential part of the felt bodily experience and a soma extension that tangibly focuses on a specific area might support the inward focus. Hence, I decided to keep the surface area of the soma extension smaller to focus on the core of the painful area rather than on the areas where it spreads. The core of my pain was in my right scapula; accordingly, I downsized the form of the soma extension. The second iteration of *Squeaky/Pain* has the flat pattern of a scapula and a three-dimensional expression of pain extends from it (Figure 12). The second iteration was designed by reflecting upon the insights gained from the participant study. As referred to in the reflective practice (Schön, 1984), each action taken in the design process was observed and the reflections on these observations informed the next steps in the research.

In addition to the improvements made to the visual form and the synchronisation, the sound-movement interaction was also altered by adding pleasant sound feedback. I used calming atmospheric sound as pleasant feedback inspired by the music I listened to during yoga meditations. In this version of the soma extension, the total time of the sound-movement interaction lasts nine minutes, the first seven minutes mediate the squeaky wooden sound and the last two minutes mediate a calming atmospheric sound. Following this, the next step was to conduct the first-person experiment to analyse my experience with *Squeaky/Pain* to explore its somaesthetic properties.



Figure 12. The second prototype of *Squeaky/Pain*. Photograph by Mehmet Can Boysan

Even though I know the working principles, I cannot, I could not hack this [the interaction]. It requires bodily exploration. (self-report, Interview 2)

To analyse the somaesthetic qualities, specifically the ability of *Squeaky/Pain* to guide the inward focus, I first needed to understand how my knowledge of the working principles of the soma extension influences my own experience with the soma extension. As I reported during Interview 2, my previous knowledge

could not help me to hack the interaction to keep the annoying sound at a lower level. The sound gets less loud when the body is moving slowly; therefore, I had to explore various movements with my body and find the slowness that would keep the volume down. Contrary to my explicit knowledge about the soma extension, I needed to acquire embodied knowledge. From this experience, I also realised that it was not necessary to inform the participants how it works before they wore the soma extension. As my experience with the soma extension in the third phase illustrates, the background information on how *Squeaky/Pain* works did not prevent me from having a somaesthetic engagement with the soma extension.

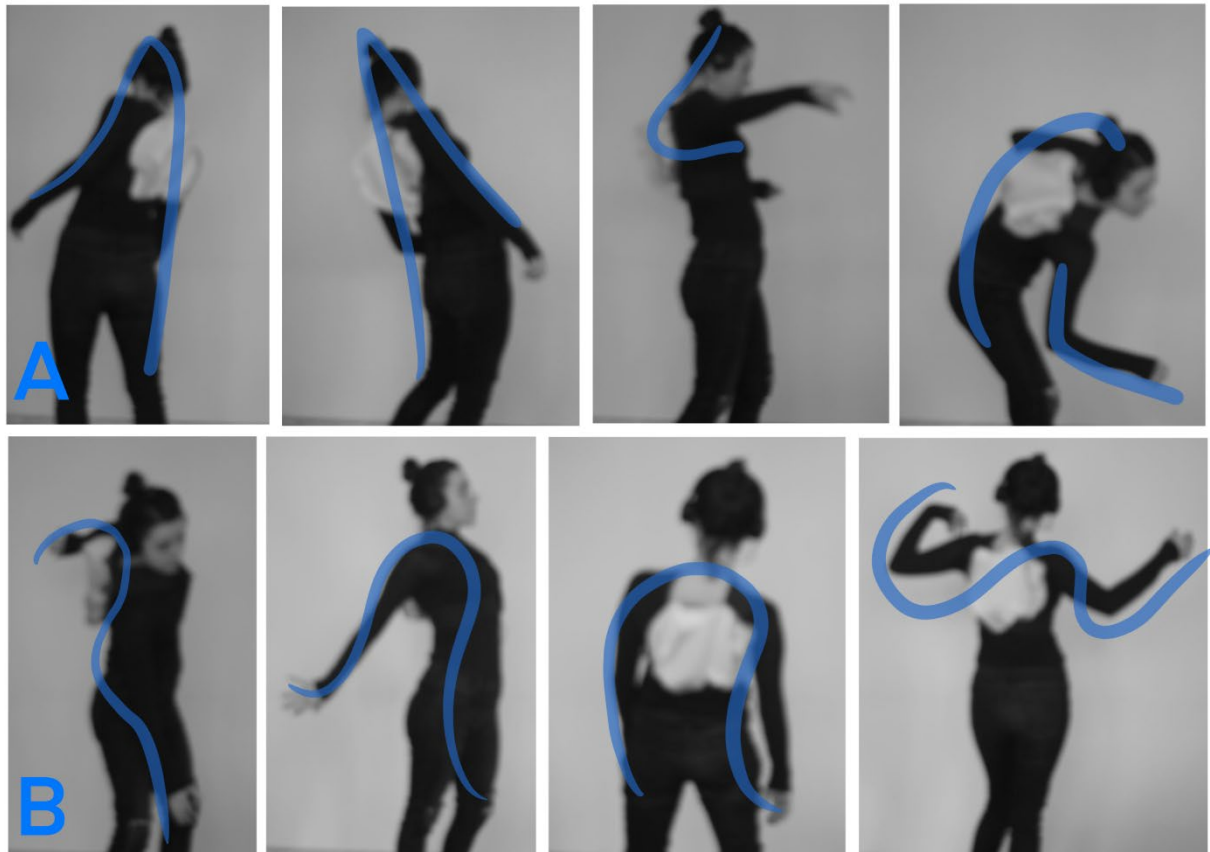


Figure 13. I am moving with the soma extension. Illustration by Arife Dila Demir

Sounds felt like my body was talking to me. When the sound was louder [in the first part], it was annoying. In the second part [two minutes of calming sound] I wanted to hear the sound more, it was even good when it was less loud. I was more in the realm like I am moving and there is this nice sound that accompanies my body. And as I am moving it is responding to me. So, it was like how I respond and how it responds to me. (self-report, Interview 2)

The next analysis involved understanding where my focus was during the interaction. The sound was a distinctive element of the experience but did not take my attention away from the movement. Rather, it guided me to focus on my movements. During the first disturbing part of the sound interaction, when the sound was loud, it grabbed my attention for a moment but later I focused on finding the balance in my movements to keep the volume down. As stated in my self-report above, both the disturbing and pleasant sound feedback guided my awareness on the movements and, through the movements, my implicit bodily experiences. Both sounds evoked different emotions and feelings, so that I perceived my body differently

in both stages and moved accordingly. These different movements are shown by the blue lines in Figure 13. Bresin et al. (2010) reveal the ability of different sounds to make people walk faster or slower regardless of their emotional intention. This suggests that it is possible to alter people's perceptions and movements through different kinds of sound feedback and aiming for somaesthetic awareness. For instance, during the disturbing sound interaction, I felt like my body was heavy and stiff; this feeling made me perform more forward bend movements as I wanted to be smaller (Figure 13A). During the pleasant sound interaction, I wanted to open my chest, arms, and legs with the feeling of relaxation and weightlessness (Figure 13B). Therefore, both sounds guided me to attend to my movements by making me move in certain ways. The influence of the sound feedback on the movement was essential for understanding how the wearer cultivates the somaesthetic understanding through bodily interactions.

The sound was like coming from my body, from my movements and it felt like movement and sound were affecting each other. For example, the feeling in the first part was stiffness, so it orient me to perform more forward bent positions and the second part oriented me in a direction where I wanted to open my chest, arms, legs, etc. I wanted to close and get smaller in the first part whereas the second promoted openness. (self-report, Interview 2)

It felt like the exaggerated version of how our bodies may talk; even without this [the soma extension] our bodies generate some sounds, but this was like the face. A sound that you cannot avoid, so, it was like a powerful manifestation of talking bodies. (self-report, Interview 2)

The design research process started with my first-person somatic experience and was finalised by returning to it to test the second design iteration of *Squeaky/Pain*. In this last phase, the focus was on the soma extension's somaesthetic qualities, specifically its ability to guide the inward focus. As opposed to the first design iteration, pleasant sound feedback in the second iteration was combined with disturbing feedback. The study showed that the pleasant and disturbing sound feedback complemented each other to guide the focus of the wearer to the body movements and through the implicit bodily experiences. In addition, with the use of pleasant sounds, the soma extension mediated the complementary experience of pain, from agony to relaxation. Finally, the improved synchronisation of the sound-motion interactions showed that, when in sync, the disturbing sound is not a hitch for somaesthetic engagements.

3.3. Reflections on *Squeaky/Pain*

Your tissues are not the problem. Changing habits of how you perceive is a good solution.

(Haines, 2015, p. 30)

Squeaky/Pain explored ways of cultivating and explicating the felt nuances of the pain experience through applying first and second-person research in tandem to inspire the design of soma extensions. This case study revealed design implications for close-to-body interactive artefacts and non-habitual bodily interactions, and brought methodological insights to elicit the felt experience of pain. It was the first design exemplar of the design programme I later named *designing with discomfort*, which is the main contribution of this PhD and will be discussed in detail in Chapter 7. In the following sub-sections, I will reflectively analyse the design process and outcomes of this case study and present my reflections under three themes: 1) affordances and frictions of the soma extensions, 2) tools for eliciting first and second-person experiences, and 3) design implications for non-habitual bodily engagements.

3.3.1. Affordances and Frictions of Soma Extensions

The affordances and frictions of soma extensions can portray the lessons learnt from the design process and the use of *Squeaky/Pain*. They inform the design qualities of close-to-body artefacts that aim to facilitate the sensory awareness of bodily discomforts. I will touch upon three notions where the affordances and frictions of *Squeaky/Pain* are situated: 1) materiality, 2) mindful engagement with pain, and 3) synchronised bodily interactions.

Soma extensions focus on explicating qualities of pain to mediate discomforting interactions and non-habitually engage with the body in pain to develop new bodily perceptions. To do this, they are required to hold the qualities of pain and reflect these qualities through their interaction modalities. In all the iterations of *Squeaky/Pain*, I played with tactile and auditory materials to mimic the pain experience. For instance, through textile materials and techniques, I manifested the lived experience of pain as tangible artefacts (see section 4.2 *Design Process*), and through sound I manifested the disturbing and relieving qualities of pain. In making the artefact, I did not intend to create a disturbing sensation through the tactility, rather I aimed at making a comfortable wearable item and solely explicate pain through the visual qualities of the textiles. However, the soma extension became a little tighter for P2 on the arm section and the feeling of tightness and pulling reminded P2 his arm pain. Yet, the tactile feeling of the artefact for the other participants and for me was more relieving than disturbing. In addition, the participants that used the first iteration all mentioned that the sound evoked similar feelings to their pain experiences and when I tested the second iteration on myself the relieving sound feedback corresponded to my somatic sensations. In addition, the tactile and auditory material qualities of the soma extension afforded conscious attention to the bodily sensations regarding pain. For example, the sounds that were reminiscent of the relieving and disturbing qualities of pain encouraged the participants to move and develop new bodily perceptions, while the tactility provided local awareness. Respectively, I propose that designers engage with different intangible and tangible sensory materials, such as sound and textiles to explicate the discomfort in question.

On the other hand, my experiment with the second iteration became a mindful engagement with pain, where I practiced communicating with both the disturbing and relieving qualities of my pain through bodily movements. This interaction brought forth the notion of mindfulness with pain through engaging with the poles of agony and relief in the pain experience. I discussed that developing new perceptions in relation to pain was necessary in the experience of this chronic condition in order to cultivate somaesthetic awareness. *Squeaky/Pain* made this possible through mediating different aspects of pain, and putting them in communication with the body in motion. As I mentioned above, for P2 the tactility of the artefact mimicked the pain experience and became a distraction from mindfully engaging with the pain. To prevent such disruptive frictions, I propose designers carefully design the wearability of the close-to-body artefacts. In addition, *Squeaky/Pain* illustrated that the synchronisation of the interactive stimuli with the body is essential to maintain the focus of the wearer on the bodily sensations. Höök (2018) discusses that immediacy and synchronisation are important to design meaningful and somaesthetic interactions. When the interactive systems are not in harmony with the bodily rhythms, they may disrupt conscious bodily awareness and hence hinder somaesthetic realisations. For instance, the first iteration of *Squeaky/Pain* glitched in terms of synchronising the sound to the bodily movements causing friction for the wearer, and claiming attention. This aspect was improved in the second iteration and the wearer was able to dive into the sensory exploration of bodily movements in relation to the pain.

3.3.2. Tools for Eliciting First and Second-Person Felt Experiences

This case study revealed that cultivating the felt experiences of first and second-person perspectives provides a rich understanding of the studied bodily phenomenon, which can be used to design impactful

interactions. When designing bodily interactions, cultivating first-person experiences can extensively inform the design outcomes (Höök et al., 2018; Núñez-Pacheco & Loke, 2020), whereas gaining second-person insights can bring forth different perspectives on the phenomena in question (Neustaedter & Sengers, 2012b). For *Squeaky/Pain*, I was first inspired by my chronic pain experience to design the first iteration, and then, by testing this iteration with other people who experience pain, I collected second-person insights into the affordances of the soma extension in relation to pain to further iterate the artefact. To cultivate lived experiences, I used kinesthetic engagements, and more specifically to examine my pain experience, I practiced yoga. In addition, the tests involving the participants was based on movement-based interactions with the soma extension, and similarly, in the third phase, I explored the somaesthetic qualities of the second iteration of the soma extension on my own body by moving with it.

The cultivated lived experiences needed to be explicated to become graspable through elicitation methods; hence, designers can make sense of them by articulating particularities to inform their designs. In designing *Squeaky/Pain*, I employed several visual and textual elicitation tools to elucidate felt experiences. Visuals and texts are discussed as complementary tools that may reveal otherwise latent aspects of lived experiences in the sole use of either one (Demir et al. 2022; Demir et al., 2023). With various aims, I applied different methods to elicit first and second-person experiences, as shown in Table 4.

Table 4. Methods applied to elicit felt experiences from the first and second-person perspective in relation to pain to then facilitate informing the design of the artefacts

Method	Aim	First-Person Perspective	Second-Person Perspective
Journal	The journal is used to capture the written reflections and verbal metaphors of the felt experience of pain.	*	
Video	Video recordings are used to capture the temporal qualities of the moving bodies to later analyse the felt qualities.	*	*
On-photo body map (On-photo BM)	A body map drawn on a photo of a person is used to precisely illustrate each experience that occurred in the body in performing specific movements.	*	
Real-size body map (Real-size BM)	The real-size body map is used to allow the person to freely express and locate the pain experience.	*	
Traditional body map (Traditional BM)	The traditional type of body map is used to document the felt experience of moving with the soma extension.		*
Semi-structured in-depth interviews	The interviews are used to gather information about participant pain experiences and their experience with the soma extension.		*
Self-Interviews	The self-interviews are used to gather information about the designer-researcher's pain experience and her experience with the soma extension through a voice recording.	*	

The application of these methods is entangled; that is, the methods were not applied separately. Rather, the application of one informed and inspired the use of the other method. In many cases, visual elicitations produced textual articulations, and textual elicitations promoted the creation of visual elicitations. In the process of designing *Squeaky/Pain*, all phases started with the video elicitation of movement-based interactions. Video recording captures the interaction and communication happening in diverse settings (Pauwels & Mannay, 2020); it can illustrate the intricacies and trivial details of interactions that may be hidden in a sole observation, thus revealing fine nuances of the experiences (Given, 2008). Analysis of video recordings is an interpretive activity that does not solely focus on describing the happenings in the video but on disclosing the meaning behind the visual processes through textual reflections, extracting hermeneutical knowledge (Pauwels & Mannay, 2020). I employed video recordings to document my yoga sessions and the soma extension sessions with myself and the participants.

As mentioned, the use of the elicitation methods informed one another. For instance, I used the video recordings of my yoga practice to create still images of each movement I performed to create photo body map drawings as somatic experience maps (Figure 7). In doing so, the peculiarities of my felt experience emerged in my journal unfolding in each movement represented in the somatic experience map as visual expressions. The elicitation of my yoga practice in relation to pain through these visual and textual tools guided the process of designing the first iteration of *Squeaky/Pain*. In the second phase of the design process, I used participant video recordings to extract the meanings of their interaction with the soma extension that remained unnoticed from the interviews. Hence, I was able to elucidate textually inarticulable aspects of the lived experiences. In the third phase, I used video recordings of my interaction with *Squeaky/Pain* to analyse the possible differences that may occur in interacting with two different sounds that were mediated by it. Similar to the somatic experience map, I created photo body map drawings to visually represent what kinds of movements were guided by each sound. While doing this analysis I was also informed by my self-interview, where I mentioned how each sound influenced my movements.

Photo body maps may encourage people to be more specific in their reflections as the images are relatable to their bodies, and the photos may evoke their past experiences (Harper, 2002). In this dissertation, I employed two other versions of body maps: 1) actual-size body maps, and 2) traditional body map drawings. An actual-size body map drawing provides a bigger canvas for people to capture the exact location of their pain experiences that may also inform the form and shape of the close-to-body artefacts (Figure 8). The most common application of body maps is traditional black-outlined illustrations that are used to illustrate the felt experiences revealing unspeakable aspects of such experiences (Cochrane et al., 2022, 2022; Gastaldo et al., 2018). I applied traditional body maps during two interview sessions with the participants conducted before and after engaging with the soma extension. Hence, I was able to see the differences that occur in their bodily sensations after engaging with *Squeaky/Pain* as well as the influence of wearing the soma extension on the participants' somas.

As a textual elicitation, I utilised a journal to document how I felt after each session of my yoga practice. The consistent use of the journal created a narrative of my unfolding experiences during the study and highlighted nuances of my pain experience that inspired the design of the artefact. Through the semi-structured interviews (Frances et al., 2009; Given, 2008) the participants' experiences became graspable for me. Similarly, my self-interview after using the soma extension worked as an audio journal unravelling the nuances of my felt experiences through textual expressions. I offered these visual and textual elicitation tools to articulate first and second-person felt experiences and rather than using them

separately I suggested combining their use to unveil the versatile aspects of lived experiences for use in design.

3.3.3. Design Implications for Non-habitual Bodily Engagements

This case study exemplified that when combining disturbing and pleasant experiences with kinesthetic engagements, focusing inward can be sustained to facilitate somaesthetic awareness. The main reasoning behind highlighting the disturbing qualities is that bodily events that cause discomfort are an inevitable part of everyday life for people with chronic conditions. In the context of pain, there are two poles: agony and relief. In everyday life, an individual with chronic pain may experience one of these poles or something in between. Considering that pain is always residing in the body, it is essential to learn how to listen, communicate, and be aware of it. Some individuals may excessively sensitise themselves or tend to ignore bodily sensations related to pain. Neither of these methods is useful for the everyday struggles with chronic pain. To ‘enhance’ the quality of everyday life, I speculated the need to learn to focus inwardly on the existence of bodily discomfort. In heightening somaesthetic awareness, *Squeaky/Pain* demonstrated an example of how disturbing and pleasurable experiences may incorporate sensitising people to pain and encourage their conscious movement of and engagement with their bodies. It did this by providing the option of movement-based communication with pain through sound, thus mediating non-habitual bodily interactions that supported the cultivation of new bodily perspectives.

Therefore, *Squeaky/Pain* brought forth two insights into the concept of non-habitual engagements: 1) creating disturbing experiences in relation to bodily discomfort, and 2) mimicking its qualities through sound. Tennent et al. (2021) discuss defamiliarisation as a soma design trajectory that may guide the awareness of a person to the intended object by making a familiar situation strange. Lian Loke and Toni Robertson (2017) suggest that by engaging with non-habitual movements we can re-acquaint ourselves with ourselves and our bodily experiences. In terms of kinesthetic engagement, in this case study, I aimed at defamiliarisation by slowing down the movements of the wearer and, as a result, making something very natural like moving become strange. This is sustained via the sound-motion interaction, where the wearer is forced to move slowly to keep the volume of the disturbing sound down and that of the pleasant sound up. In the context of pain, Aneesha Singh et al. (2015) exemplify movement sonification for promoting confidence in physical activity despite chronic pain. Similarly, through the sonification of movement, *Squeaky/Pain* influenced the wearer’s body perception by mimicking the pain experience via sound and altering the volumes of the sound in relation to the speed of body movements. The study successfully showed that sound interaction can mimic the pain experience and that engaging with sound-motion interactions can alter people’s perception. Mediating discomforting interactions helped people to connect and communicate with their pain through this sound-motion to facilitate an unusual experience. In designing for pain and bodily events that cause discomfort, I suggested using sound as a medium to explicate the discomfort and support the kinesthetic interactions.

3.4. Summary

In this case study, I examined *how the experience of chronic pain may inform the designing of soma extensions*, thus exploring ways of translating the pain experience into designed artefacts. With no prespecified ideas in mind, the project began with a first-person exploration of my pain experience. In addition to literature about pain, the collection of my subjective pain experience formed the initial design ideas that aimed to address people who have chronic pain. Later in the process, pain experiences of other people were also included in the study to gain an in-depth insight into the studied phenomenon, pain. I concluded the study with a first-person exploration of the second iteration of *Squeaky/Pain*. The study illustrated how pain can be translated into the design of close-to-body interactive wearables and how

discomforting experiences can facilitate somaesthetic awareness. In doing so, it brought forth three insights into addressing the main research question: 1) affordances and frictions of soma extensions, 2) tools for eliciting first and second-person experiences, and 3) generative design implications for non-habitual bodily engagements. The affordance and frictions of *Squeaky/Pain* discussed how artefacts can be designed to resonate with other people's pain guiding them to mindfully engage with their pain and the importance of building synchronised feedback to support somaesthetic awareness. The elicitation tools included visual and textual elicitations of felt experiences that aid the process of translating pain into interactive artefacts. The generative design implications for non-habitual bodily engagements suggested explicating discomfort and mimicking discomfort via sound to create non-habitual interactions that may lead to new bodily perceptions. While illustrating a promising insight into the use of discomforting elements for the cultivation of the somaesthetic awareness of pain, the project also revealed the need to enhance the bodily engagement of the soma extension to promote better somaesthetic interactions. Accordingly, I will scrutinise how to promote engaging bodily interactions via soma extensions in the second case study.

CHAPTER 4



Photograph by Nesli Hazal Akbulut

4.CASE STUDY 2: CARING COMPANION

Good News: It turns out understanding pain is a very good way of relieving pain.

(Haines, 2015, p. 3)

Knowing that we have chronic pain does not necessarily mean that we understand the pain. The information about having chronic pain does not provide access to the felt affective qualities of it for the body experiencing the pain. To access those qualities, the person needs to build deliberate communication and an intimate relationship with her implicit bodily happenings. Apprehending the felt qualities of the soma may help a person with chronic pain to adopt caring actions to cope with the pain. I interpreted the melioristic approach of somaesthetics as ‘becoming with’ instead of ‘improving’ and therefore aimed to design for people to be with their chronic pain, accepting their messy changing bodies and negotiating new ways of living. In other words, I aimed to build a corresponding relationship between the body and pain. Correspondence is a process by which beings and things respond to one another (Ingold, 2017). I regarded correspondence as an intimate and sincere communication between the body and pain that develops from the cultivation of somaesthetics awareness. When designed carefully, soma extensions can create such a communication by mediating engaging bodily interactions. Case Study 2 *Caring Companion* examined ways to support people’s interaction with their chronic pain to build a conscious and intimate relationship with their bodies. A soma extension can become a caring companion for people in pain to help them get through difficult experiences, creating a space for them to kinesthetically engage with their pain and articulate their experiences through reflection. In doing so, it helps them cultivate caring practices to become new with their bodies in pain.

4.1. Aims of the Second Case Study

The first case study *Squeaky/Pain* showed that soma extensions that mimic the pain experience may resonate with other people’s pain experiences, yet mediation is crucial for better engaging the wearer’s interactions. *Squeaky/Pain* revealed that the synchronisation of the sound feedback and better fit on the body are necessary elements to support bodily engagement. The participant study illustrated that the pain experience of others can unveil the otherwise unnoticed aspects of this discomforting experience that can benefit the design of the soma extension.

Accordingly, in the second case study, I examined the question: *how may soma extensions be designed to promote engaging bodily interactions with people with chronic pain?* In the first case study, the cultivation of my first-person experience of pain was unfolded over three weeks which provided deeper insights into my experience. In the second case study, I aimed to acquire a deeper insight into the felt experience of other people living with musculoskeletal pain. Hence, to explore this question, I conducted a cultural probe kit study (Gaver et al., 1999) that included the third iteration of the soma extension aiming to cultivate the felt experience of chronic pain in others over a relatively long-term period, over three weeks. The probe kit included elicitation tools informed by the first case study, such as journals, body maps, plasticine, and others for the participants to document their experiences after each engagement with the soma extension. *Caring Companion* became part of the participants' lives and acted as their comforting as well as disturbing companion in dealing with chronic pain. It revealed significant insights into the participants’ lived experience of chronic pain, illustrating five different stories of being and living with pain. In what follows, I will illustrate the process of designing *Caring Companion* and discuss its analysis and preliminary results.

Interlude: Designer's Autoethnographic Reflections on Pain

When I started the first case study the only chronic pain experience I had was upper back pain that spread around the right side of my neck, shoulder, and scapula. Later, I was diagnosed with IBS (Irritable Bowel Syndrome) and SIBO (Small Intestinal Bacterial Overgrowth), and some additional things that are related to these two main diagnoses. What it means to diagnose with IBS/SIBO is that you experience agonising abdominal pain in addition to a myriad of unpleasant symptoms that come with it. Many of these symptoms entail unintentional changes in everyday life and they challenge the social taboos and shame, creating the pain of being a diseased body in the outside world. In addition, there is also the pain of learning about this new body that feels like an alien or possessed to be able to function again.

With the emergence of these new bodily discomforts, I decided to keep a pain journal just to note the high points of my pain and discomforting experiences, not necessarily the agonising points but also the empowering ones. This journal was not meant to be later used or analysed for my PhD, rather it was just for myself out of curiosity. Yet, as I explored chronic pain and bodily discomforts in my research, I cannot claim that the journal was of no help in gaining insights into pain. This journal did not consist of mere writings but it was more like a drawing journal that sometimes included some textual reflections. After half a year or so I read my journal from the beginning and realised some entries were uncovering some qualities of chronic pain and chronic discomfort. Then I decided to approach my journal as an autobiographical research material and started to work on composing a pictorial [an academic writing format where the visuals play an important role in mediating the knowledge] from it. Once I finished the pictorial for submission I felt naked, vulnerable, and heavy, feeling that I had opened up very intimate information without even thinking of myself as a human who feels and senses. I realised that there was too much information out there, and I was not even sure whether I was okay with it.

Following that, I took a few days to think about whether I wanted to submit this paper as it is, change something or not use it at all. I re-read it and extracted the parts that made me feel uncomfortable and submitted it. To me sharing my intimate data was part of my journey of becoming anew with my pain, I feel being vulnerable is an empowering situation. It was challenging the taboos and shame that emerge in experiencing discomfort in social situations. Yet, this writing experience made me realise how easy it is for an autoethnographic researcher to take herself for granted and approach herself as the object of the research. Additionally, I also realised that a consent-based ethical approach to working with people might not be enough, especially when working with vulnerable and intimate topics; hence, I started to look for more caring approaches to conduct my autoethnographic research.

4.2. Design Process

Caring Companion is the name of the soma extension and the cultural probe kit that were designed for the second case study. In this case study, I decided to use the cultural probe kit method (Burrows et al., 2015), as I aimed to acquire the felt experience of people with chronic pain to explore ways of enhancing bodily engagement with soma extensions. Cultural probes are regarded as a tool to develop an understanding of a particular context; probes are considered an inquiry into what is meaningful for each individual regarding the context of the study (Wallace et al., 2013). Cultural probes are like interventions that influence the participants' lives while eliciting informative and inspirational responses (Gaver et al., 1999). When designing the *Caring Companion* kit, which was situated in the context of soma design, I adopted the idea of engaging with the non-habitual – breaking habits – through somatic practices for becoming anew with pain and developing an enhanced understanding of this discomforting bodily phenomenon.



Figure 14. Tangible and digital items of the *Caring Companion* kit

Inspired by the first phase of the first case study, where I conducted a yoga movement experiment to cultivate my felt experience of pain (see Chapter 4), the *Caring Companion* kit entered the everyday lives of the participants by offering a yoga practice to help them explore their felt experience of pain. In addition, the elicitation tools that emerged in the first case study were included in the kit (e.g., body maps, journal, etc.) (see Chapter 4). More specifically, the kit includes tangible and digital items (Figure 14). The tangible items include a soma extension, a journal, 12 body maps, 12-word lists consisting of 42 pain expressions, coloured felt-tip pens, plasticine, a calendar, and a 'how to use the kit' booklet. The digital items are two yoga videos uploaded on YouTube, one for upper and one for lower body pain, and a sound file. The participants were asked to download the sound file onto their cellphone and insert the cellphone playing the sound file in the soma extension (Figure 15). Then, they were asked to wear the soma extension, placing it where they experienced the pain (e.g., on the hip or lower back), and practice the yoga movement series shown in the YouTube videos. The participants choose to practice the series according to the location of their pains. After practicing the yoga with the soma extension, they were invited to use the journal, word lists, and plasticine to elicit their felt experiences emerging during the practice.



Figure 15. The image shows how to insert the cell phone (that plays the sound) into the soma extension. Photograph by Nesli Hazal Oktay

I conducted the *Caring Companion* case study in November–December 2021 with five people who experienced chronic musculoskeletal pain, either on the upper or lower part of the body. Participants were recruited via an open call sent to the mailing lists of three universities in Tallinn, Estonia, and those of my network. People responded to the call by filling out an online questionnaire that was utilised to determine their eligibility. The selection criteria included that a participant must have musculoskeletal chronic pain and not have any health-related restrictions to practice yoga. In total, five from eight applicants were selected to participate in the study; three of them had chronic upper body pain, one had lower body pain, and one had both. I invited the selected participants to collect a *Caring Companion* kit from the Estonian Academy of Arts (EKA). Each participant met with me individually and I explained to them the study, how to use each item in the kit, and emailed them the digital part of the kit. In addition, during this meeting, I opened the yoga videos to explain each movement to be sure that they can practice the sequence safely in their homes. I also asked them to stop the practice if they felt any discomfort and get in touch with me. After three weeks, the participants returned their kits to EKA, where I conducted semi-structured interviews with them, each lasting approximately 40 minutes. This final interview aimed to explicate the participants' body map drawings, journal entries, word choices, and plasticine forms and to acquire any additional information that the participants wished to share. In what follows, I will present the physical and digital items included in the *Caring Companion* kit.

Soma Extension: The soma extension for the second case study was inspired by *Squeaky/Pain*, which regarded soma extensions as wearable interactive textile artefacts mimicking the agonising and relieving

qualities of a pain experience (Demir, Nimkulrat, et al., 2022). The first case study illustrated that the soma extension created a local awareness, bringing conscious attention to the area it was placed on. Accordingly, I designed a soma extension in an ambiguous form to be worn on any part of the body that has pain to support local awareness (Figure 16). It was made using the highly elastic soft viscose fabric used for producing underwear to create a softer sensation when touching the skin. It had two sides: one touching the body and one facing outward when worn. Its filling material created a hard and irregular texture inside the area that faced the body. The other side had a thick layer of felt that worked as a pocket for inserting the cellphone to play the sound. The soma extension was designed so a cell phone could be inserted inside to create the feeling that the sound was coming from within the soma extension. Since I did not aim for digital interaction using sound, using a cellphone to play the sound was the most convenient and accessible solution for this case study. Hence, the soma extension mediated auditory and tactile experiences for the wearer.



Figure 16. The soma extension, *Caring Companion*, designed for the second case study. Photograph by Nesli Hazal Oktay

Sound Files: Various auditory stimuli show an impact on body perception and bodily movements (Bresin et al., 2010; Singh et al., 2016; Stanton & Spence, 2020; Tajadura-Jiménez et al., 2014). For instance, a creaky wood sound induces the perception of back pain (Stanton & Spence, 2020), whereas a muddy ground sound makes people walk slower, and the sound of icy ground makes them walk faster (Bresin et al., 2010). Therefore, sound influences how people move and what and how they perceive in relation to their bodies. The first case study showed that disturbing and pleasant sounds were complementary in terms of mimicking the pain experience through sound-motion interaction (Demir, Nimkulrat, et al., 2022). Accordingly, the sound file used in *Caring Companion* consists of two different tones: one disturbing sound representing the agony of pain, and one pleasant sound corresponding to the relief from pain. The sound sequence, 17 minutes long in total, starts with the disturbing tone and continued with the pleasant one, each lasting seven minutes with a one-minute break in between and two minutes of silence at the beginning for the participants to insert their phones in the soma extension and get ready for the movement practice.

Yoga Movement Videos: For this study, two yoga videos were created: one for people who experience upper body pain and one for those who experience lower body pain. The 17-minute videos consisted of three main movements; only the second movement in the series differed in the videos for lower and upper

back pain. The first half of the video corresponded to the disturbing sound and the second half repeated the same movements but then it was synced with the pleasant sound. It has been discussed that auditory cues can influence body perception differently (Stanton & Spence, 2020). By repeating the same movements alongside both sounds, I aimed to understand how this distinctive sound may impact the wearer's engagement with the soma extension and the perception of their movements.

Journal: The journal included in the *Caring Companion* kit was meant for participants to reflect on their felt experiences in relation to pain and the soma extension used for the movement practice. It became a tool for the participants to explicate their experiences for themselves through reflection and help me to grasp their experiences for analysis after the probe kit study. I asked participants to use the journal after each movement practice; specifically, I invited them to write about their bodily experiences during the movement practice.

Word Lists: The word list consisted of words expressing possible negative and positive feelings of pain; it was inspired by the McGill Pain Questionnaire (Melzack, 1975), yet the aim was not to objectify the pain experience of individuals. Rather, I attempted to understand how people would refer to their experiences and whether the explicit interaction of pain from agony to relief could simultaneously create both negative and positive feelings. Since I appreciated the struggle to express the pain and discomforting experiences and their influence on the language, I asked participants to add any word they wanted to the list, even in their native languages.

Body Maps: In the articulation of felt experiences, verbal and textual tools may not be enough to access the hidden dimension; visual elicitation methods can be used as complementary tools (Demir, Kuusk, et al., 2022). Body maps can explicate the hard-to-speak felt sensations and elaborate the felt narratives (Cochrane et al., 2022). However, body maps generally have a black outline and a slightly masculine shape in a standing posture, palm facing outwards. I argued that such traditional body maps are limited when explicating various sensations that emerge in different movements. For the *Caring Companion*, the body maps were designed to indicate each posture. They were drawn from the photos of me practicing the yoga movement sequences.

Plasticine: In a similar attempt to support the articulation of felt experiences using visual mediums, I added plasticine for the participants to reflect their bodily experiences in a 3D form. In total, the participants did 12 movement practices and used each articulation tool after each practice except the plasticine. They were asked to use the plasticine six times when they felt like they had an important or distinctive experience during the movement practices.

Felt-tip Pens: Various colours of felt-tip pens were part of the kit inviting body map drawings and possibly journal entries as well.

Calendar: An A3-size calendar helped the participants to keep track of their practice routines.

'How to Use' Booklet: The A5-size booklet introduced the items in the kit and the study itself as well as how to use the kit. In addition, the booklet had the consent form that stated the aim of the study, participants' right to withdraw from the study, and clauses where the participants might or might not agree on the different usages of their data. After being informed about the study and reading the consent form, participants are asked to sign the form on the day that they receive the kit; however, the forms are collected when they return the kit.

4.3. Autoethnographic Reflections of the Participants: Living and Being with *Caring Companion*

Through *Caring Companion*, I collected the felt experiences of people experiencing chronic pain; I then analysed the probe kits aiming to portray the participants' individual stories, illustrating how their somaesthetic journeys unfolded over three weeks. I took inspiration from a paper that employed storytelling to transfer the individuals' transformative becomings and entanglements with the prototypes (Ståhl et al., 2022) in the context of soma design. Therefore, I decided to adopt narrative inquiry. Narrative inquiry is a microscopic examination of an experience as a narrative phenomenon; hence, it makes it possible to study the individuals' experiences intimately over time in the given context (Given, 2008). I studied each participant's stories by looking at all the visual and textual data collected from them, including journal entries, word lists, body map drawings, and tangible reflections formed with plasticine. Accordingly, I decided to present their somaesthetic narratives in the form of journal entries by re-writing their journals and re-drawing their body maps based on the data that they provided via the cultural probe kit.

In doing so, I did not add any fictional element into their visual and textual narratives. Rather, I combined the information given by them and presented it concisely without losing the original content of their living and being with *Caring Companion*. Narrative inquiry actively involves participants in the writing process and negotiates each entry with them before publication (Given, 2008). A similar participatory writing approach is suggested in life writing about illness and disabilities, as it is a sensitive topic, and the patients are often in a vulnerable position (Couser, 2018). When signing the consent forms, the participants agreed on the publication of their data anonymously; however, to take a caring and ethical approach to publishing their narratives, I sent the re-written and re-drawn narratives to the participants asking them whether they would like to add, delete, or change anything. All the participants confirmed the re-written and re-drawn narratives. Additionally, I gave the participants pseudo-names, Olivia, Lily, Hazel, Ava, and Chloe, which were approved by them, to maintain their anonymity.

I consider this section *Autoethnographic Reflections of the Participants* and present it similarly to my *Autoethnographic Interludes*. I portrayed the participants' somaesthetic unfoldings from their voices using the first-person viewpoint. Accordingly, 'I' that is used in participants' narratives represents respective participant. I deliberately employed this method rather than presenting their stories through concept mapping (Given, 2008) or thematic analysis (Braun & Clarke, 2019; Kiger & Varpio, 2020), as such methods might lose the peculiarities and specifics of each participant's journeys. In addition, I aimed to invite readers to each participant's living and being with *Caring Companion* to gain a better understanding of their experiences. In doing so, I wish to reflect on the hardship of cultivating a somaesthetic awareness of chronic pain showing that it is not a linear journey, rather it is a challenging exploration. Accordingly, in what follows, I will present the participants' visual and written narratives.

Olivia's Narrative (Figure 17)

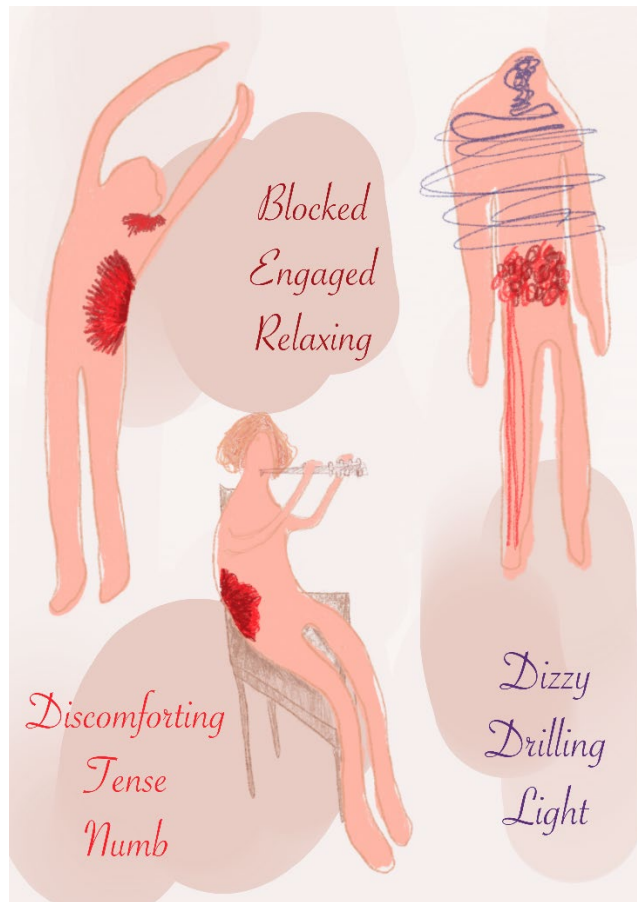


Figure 17. Regenerated body map and textual elicitation of Olivia's Narrative by the designer. Illustration by Arife Dila Demir

I am an oboe player experiencing upper back pain that became chronic in 2019; it is like a heavy knot in the middle of my spine. I have been practicing yoga and using some massage tools to relieve my pain, yet I have never built an exercise routine for my pain. My pain is mostly triggered by lengthy orchestra practices, carrying heavy bags, and sitting for long hours in front of the computer. Hence, almost all my daily activities are pain triggers. I was really curious about this study and started the first practice the day after I received the kit. Since my first practice with *Caring Companion*, I was intrigued by the sound and tactility of it and how it resonated with my body. After my first practice on 1 November, I wrote:

I started to feel the pain behind the soma extension during the practice; however, it faded away towards the end. It is weird because the pain sensation is kind of there but also not. The noises of the first half of the sound file were annoying but also weirdly pleasing in the stretching part, where they matched the stretching movement.

On the next day (2 November), different pains were claiming my attention as I noted:

I am so much in pain today, also an extra pain emerged in the right leg. After long hours of sitting, I feel like my body became one with the chair, the chair is not there anymore but I can still feel it.

Then I also realised even though the pain is there every day it feels different, and I feel different accordingly. On November 4, I wrote:

It's interesting to fully realise how every day I feel different. More pain, less pain, joints cracking, weakness, or energy. It's the same body but until now every day was very different from the previous. I'm curious how it will evolve, especially when I am on my period it affects my pain level a lot.

On November 10, during the practice, the sounds of the soma extension were in harmony with the sounds of my ankle and the wooden floors of my room.

My ankles cracked a little like the first sound, plus I walk on wooden the floor so sometimes it cracks too. These sounds take my mind away from daily worries.

November 10 was a relatively good day, the practice revealed rigid parts of my body though it was not painful.

In general, it was a good body day; however, the last stretch was my least favourite of the day because it makes me aware of how little flexible I am...my back felt made out of bricks. To clarify, I didn't experience a lot of pain rather felt active...just a bit tired of my non-flexibility... my regular rigidity.

I started to gain some new insights regarding my pain that were unnoticed previously, on 20 November I recorded:

My lower back bothered me a lot during the practice. When stretching the left side was worse than the right side. This I found very interesting because previously I never recorded the difference between sides. Though it also makes sense because my pain knot is slightly on the left side of my spine.

I am now trying to be more conscious about how I use my body, but of course it is not easy to pay the same attention every day. On 21 November, I noted:

Some days I was able to attend more to how I sit in the orchestra, how I approach my instrument and how I carry it. And those days I was not in so much pain even after sitting 3 hours but today is just not one of these days.

Lily's Narrative (Figure 18)



Figure 18. Regenerated body map and textual elicitation of Lily's Narrative by the designer.
Illustration by Arife Dila Demir

The pain first emerged in my right shoulder and then spread to my neck and arm. I do not remember when it first started but it has been at least four years. The pain is not active every day, but I experience pain attacks two to three times a month that sometimes lasted a day sometime a week. I used to apply some creams or take painkillers to relieve the pain, I still use the pills but have dropped the creams. I now apply hot water bottles to the painful area. In general, lifting heavy things or sitting for long hours in front of the computer triggers my pain. For me, the most important realisation that this study brought forth is how hard it is to take deep breaths into my belly and how I can soften this area. On 9 November, I noted:

The most important thing that I realised today was how hard it was for me to breathe into my stomach. I can't stretch my stomach area to breathe whenever I do breathing practices in my personal life. I feel like there is some kind of barrier that prevents the air from filling in. And I felt the same during the movement practice.

On the next day I realised that even for a short time the pleasant sound was helping me to focus on my breathing and helped me to better concentrate on my daily tasks that day as well.

...also, I can definitely focus on breathing in the first few minutes of the exercise with the second music.... I felt more relaxed after the movement practice, I feel like the breathing exercise is helping me to focus better on work as well.

The same day I realised some of the uncomfortable parts of my body during the movement practice.

Slow walking was challenging because it puts a heavy weight on my knee which I can't stand on easily. And arm movements put pressure on my lower back, it was getting forced a bit. However, I managed to stretch without forcing myself too much.

In general, the tactility of the soma extension was helping her to focus on the specific body parts that she wore; however, some days her awareness was stronger.

I had the highest awareness of the soma extension while doing the arm stretches. Through extension, I was able to keep my focus on my back and shoulder muscles and I felt that my arms got more flexible. But at the same time, I felt the pain points more, probably, it is because I was focusing on that area. But to clarify, it was not the experience of pain but just becoming aware of the pain points.

My daily struggles and stress influenced my mood during the movement practices. For instance, on 18 November, I wrote:

I was a bit stressed due to work. I also felt like it was extra hard to take deep breaths today, chest capacity felt so limited. And at the end of the practice, I felt dizzy due to trying super hard to control my breathing.

That evening I gained some realisations regarding softening my breathing which I tried to mimic during the movement practice the next day.

Yesterday evening I was angry about something related to work and I was sitting, trying to calm myself down. Then I realised while sitting it was easier to take deep breaths to my belly than standing. I tried to mimic this during today's practice....

Hazel's Narrative (Figure 19)



Figure 19. Regenerated body map and textual elicitation of Hazel's Narrative by the designer. Illustration by Arife Dila Demir

It was about three to four years ago when I started to experience pain in my shoulder and neck, and very rarely also in my hips. Stress, bad posture, and extensive use of my cellphone and laptop trigger my pain and probably they are the reason why it first started. Previously, I received physiotherapy, used painkillers, and practiced yoga and Pilates to soothe my pain. Now I continue with physiotherapy and yoga seldomly. In my experience with the kit, the sound was a prominent part of my experience, I often regarded the disturbing sound as an indication of pain whereas the pleasant sound caringly calmed me down. On 6 November, I wrote:

During the first set [disturbing sound section], the pain became even sharper but then it was relieved in the second part [pleasant sound section]. The softer tunes of the second section and the softness of the soma extension helped me to feel relief.

I think I started to build an emotional connection with the soma extension, which also helped me to reconnect with my pain differently. Through the soma extension I feel like my pain is being heard, on 8 November, I noted:

The first sound induces an awareness of pain whereas the second sound is an invitation to explore and relax. Finishing the practice is like breaking up with the extension on good terms. And at the end, the pain is still there but it feels like it is 'heard'. It is behaving now.

Some days I took an interpretive approach to walking to stay more engaged. On 14 November, I wrote:

Improvised a bit while walking. Walking is 'playful'

In general, I couldn't ignore the pain during the practices, although, I am not sure if that was the aim; however, it was not irritating every day. Some movements relieved my stiffness and heightened my bodily awareness promoting the feeling of self-care. On 25 November, I noted:

For the first time I did the practice in the evening, and it felt better. I am too stiff in the mornings. Stretching my arms softens the tight muscles around my waist, and I did enjoy it. 'Calm' is the feeling that came with the raising arm movement...Since I started this project, I have realised that I have more problems with the upper body rather than the lower. This is a nice experience. It provides a sense of self-care; however, the pain is still there, and you cannot ignore it.

As the stretching eased my bodily tension, I decided to transfer these movements into my daily exercise routine. Accordingly, on 27 November, I recorded:

My body is very stiff in general. These movements in both upper and lower body videos were a treat for my body. My body is always in need of stretching. I should start practicing yoga. During the practices, despite the feeling of stiffness, I felt like I am doing something, and this felt good. For example, I can add the 'raising arms' and 'turning hip' movements from the video into my daily routine. These movements were quite relaxing for my body.

During the study, I had good and bad days regarding the intensity of my pain. On one of the bad days, the tactility of the soma extension induced a feeling of togetherness and care. On 28 November, I scribbled:

Lower body this time! Practiced two times on the same day. The back pain got in the way again.... So, I could not connect to the hip pain...My apartment is too cold, so, I always wear a thick layer of clothes that prevents me from feeling the surface of the extension. But I can feel its existence, and this is a wonderful sensation. It was like a cute animal... wasn't doing miracles but it was there to help me. It evoked a feeling like it was saying 'okay, now relax, it will get softer, it will pass.' It was like companionship.

Ava's Narrative (Figure 20)

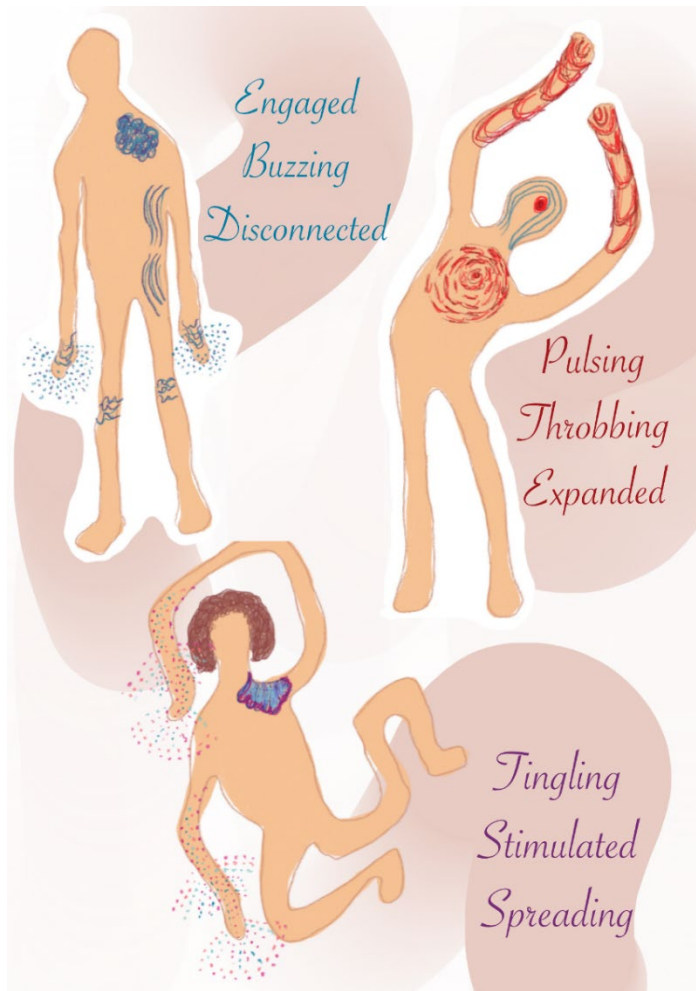


Figure 20. Regenerated body map and textual elicitation of Ava's Narrative by the designer. Illustration by Arife Dila Demir

I used to experience shoulder and neck pain occasionally which turned into a chronic experience in 2011. I have never received medical treatment for my pain but I tried yoga and massage to comfort my pain. Lately, I am mostly applying muscle ointments and doing some stretches to mitigate the discomfort. If I carry heavy bags or shoulder-strap bags, then my pain grows into an unavoidable experience. I was very attentive to the external elements that distracted me during the moving practice. On 3 November, I reflected on this:

I had a busy day and just ate junk food (burger and fries). My shoulder feels fuzzier... and I am distracted by my homework. So, I am a little frustrated writing this.

In my second practice, I felt a hot/cold tingling feeling spreading in my hands which then became prominent almost in all movement practices for me. My entry on 4 November illustrates:

I had a different sensation today, a feeling of heat right below the soma extension, and the hot/cold tingling hand feeling wasn't prominent. I felt more concentrated during the walking part and again felt the heaviness in my shoulder.

The practice was increasing my bodily awareness concerning pain which is expanded as a spatial awareness. On 6 November, I noted:

Today I vacuumed before the practice! I noticed that I would get distracted by dust and hair on the floor while practicing the slow walk, so, I wanted to stop that, and it worked. But this time my drying rack took up a considerable amount of the walking space.

On 14 November, my practice was heavily influenced by the sound of the soma extension as if the sound was echoing my body movements which also regulated how I feel.

For the first time, I did the practice before dinner, and I felt more energy and engagement. Arm stretches felt great, and I got used to the rhythm of the movements. Sometimes it felt like the movements and sound synced up in a cool way. It was weird how sometimes the sound mirrored the body, e.g., when stretching to the sides it was like my joints were cracking. In general, I also like how the two sounds were very different than each other, different but complementary. It affected how I feel in my body. The first sound was intense and the second calmer. So, I felt more engaged and stimulated in the first set and calmer in the second.

And some days I could not focus on the practice due to my anxieties related to daily life when I often felt disturbing sensations on my pain point as well. I mentioned this on 18 November:

I was very anxious today, so, I was quite distracted during the practice. There was a pinching sensation in my neck where I usually feel tension.

On 20 November, I felt the soma extension as a 'thing' that indicates the start of the movement practice as a caring act for the self that also shapes how I perceive the practice.

Doing this yoga movement practice with the soma extension is super interesting. I've done yoga before but somehow when I put the soma extension on, it kind of complements something. Like it signals the activity that I am about the start, puts me in a different concentrated mindset.

Finally, when finishing the study, I was more aware of my body, as I wrote on 22 November:

I don't know if this had to do with this practice, but I noticed that I have become more aware of my posture and I started to engage more with my shoulders in other physical practices as well. I'm really glad I participated in the study!

Chloe's Narrative (Figure 21)

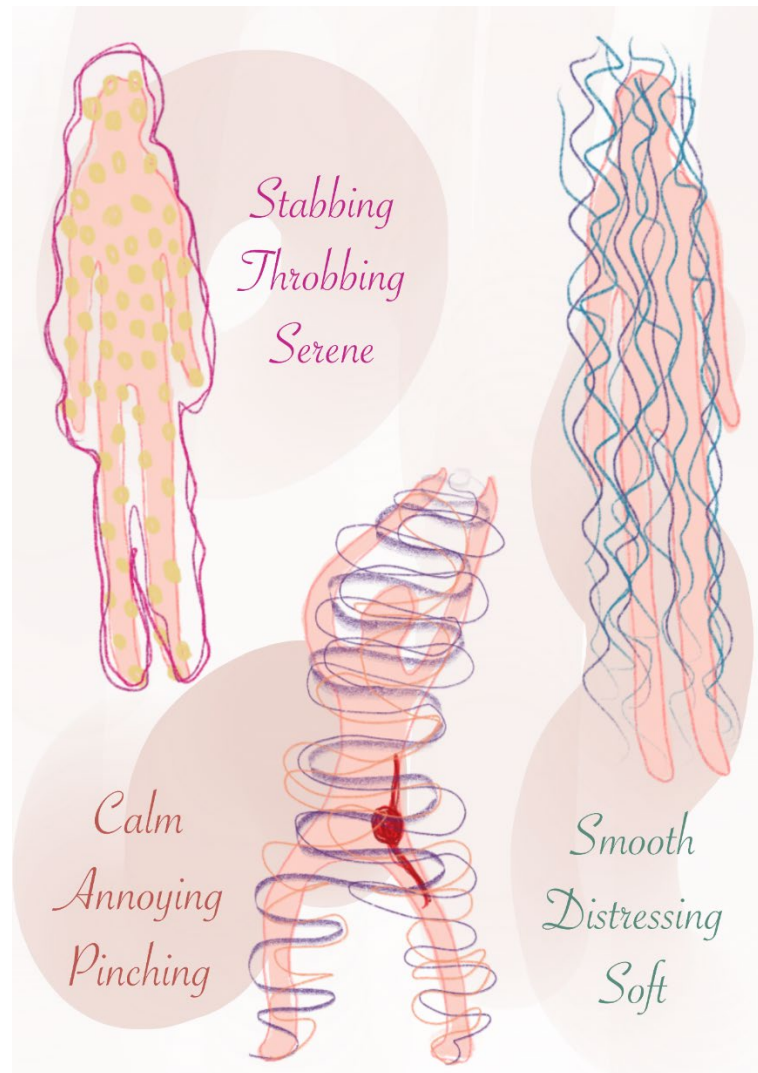


Figure 21. Regenerated body map and textual elicitation of Chloe's Narrative by the designer. Illustration by Arife Dila Demir

About six months ago I fell on my left buttock while skiing and since then I have had daily pain in my hip. I had to stop running after that, as I feel the pain strongly whenever I run after that incident. I tried massage and yoga-like stretching exercises to alleviate the pain but these days I am walking to comfort my body because sedentary days trigger my pain. Therefore, I need gentle activation for the body to alleviate the pain. To me living with the soma extension was a challenge, I found both sounds extremely annoying in my first practice, yet, later on, the second sound calmed me down. On 3 November, I wrote:

I tried to ground my jumpy mind and remind myself that this will only last 15 min. Then the mind calms down eventually. When the second sound started, I felt warm and cosy in my mind. It was not annoying like yesterday. I came into the moment of blending into the movement at the end. So, the end became meditative, also I perceived the sound as blissful

and serene. Now I sat down to write this, and I enjoyed the writing process. It is good self-practice. I am intrigued by this challenge.

The sound continued to play an important role in my experience, I was trying to make sense of how different the sounds were influencing my feelings. On 8 November, I wrote:

I could feel my hip pain today. How did the different sounds affect it? I don't think it directly effects the hip pain but the annoyance level of the sound effects mental well-being that plays a prominent role in physical healing.

Even though I was able to tune into the second pleasant sound, the first sound was almost always inducing negative feelings and focusing on my jumpy mind was the biggest obstacle for my movement practice rather than the physical constraints. Accordingly, on 14 November, I noted:

[t]he first sound induces anxiety. When the sound changes it is less annoying and it is meditative; thus, easier to practice. Finding time is challenging, the physical pain is not an issue.

Interestingly, even though the first sound echoed with the pain and frustration, with the meditative aspect of the second pleasant sound I was able to finish the practice with peace of mind. On 15 November, I mentioned:

Somehow it was easier to practice today. The pulsating sound of the first set induces anxiety in me whilst the second part brings serenity. I can feel the pain more when moving with the first sound than with the second one. The second sound is calming and relaxing so, it sometimes helped me to forget the annoying part.

As I was struggling to find a time for the practice in my mind, on 16 November, I carried the soma extension to my studio aiming to do the practice during the day, which helped me to get into the practice easier.

Since I brought the soma extension to my studio yesterday, it is now easier to practice and find some time. However, it is still difficult to concentrate on the practice. That says a lot about my (undiagnosed) attention disorder. So, this practice shows me how distracted I am. So, in this sense, it is a good practice of being present and self-grounding.

Similarly, on 17 November, the movement practice turned into a nice break to take care of my body that had been sitting for a long time.

I have been sitting all day long so the exercise was a welcome break to move today.

4.5. Reflections on *Caring Companion*

Here I will present my reflective engagement with the participants' responses to living and being with the *Caring Companion* kit. To do this, I divided my reflections into three sections. First, I will touch upon the affordances and frictions of the *Caring Companion* through analysing the participants' documentation and narratives. At the end of this first section, I will introduce five notions that are generated as a result of my analysis, as well as informed by the insights from the first case study regarding the affordances and frictions of *Squeaky/Pain*. In the second section, I will propose four actionable design strategies that are generated by the five notions. These strategies are: 1) building companionship, 2) unveiling the discomfort, 3) creating a room for improvisation, and 4) supporting somatic engagements in daily life. Finally, in the third section, I will discuss three levels of somaesthetic becomings in relation to chronic

pain: 1) instrumental awareness of pain areas, 2) the understanding of pain, and 3) corresponding to pain. The analysis of the participants' narratives suggested that the somaesthetic journey is not linear. Rather, it consists of many entangled lines, and is incremental and constituted by many layers. Somaesthetic becoming is a fluctuating life journey between these entangled layers. I discuss three levels of somaesthetic becomings in relation to chronic pain: 1) instrumental awareness of areas of pain, 2) the understanding of pain, and 3) corresponding to pain.

4.5.1. Affordances and Frictions of Living and Being with the *Caring Companion*

I analysed the participants' autoethnographic narratives of living and being with *Caring Companion* to extract the meanings and idiosyncrasies of their lived experiences. My analysis was motivated by a thematic and visual narrative approach; the thematic approach focused on what the experience was about and the insights that it provided through analysing the themes emerging from the textual narratives. while the narrative approach explicated the insights from the narratives by linking visuals with keywords (Given, 2008). Accordingly, through a thematic approach, I dissected their narratives into themes, specifically in terms of auditory interaction, tactile interaction, wearability qualities, and the qualities of the probe kit (Figure 22). I employed a visual narrative approach to explicate the engaging qualities of the soma extension according to the notions that emerged within the participants' storied life experiences., Using the Miro software, I prepared a table for the thematic analysis with the following headings: movement interaction, sound interaction, tactile interaction, non-habitual engagements, wearability and somaesthetic realizations. In analysing the participants' probe kit reflections and narratives, I added each participant's corresponding reflections under each heading. Many reflections that were placed under different headings were connected to each other; hence, they suggested that they operate as an entangled system rather than individual interaction/design modalities. This analysis helped me to explore the affordances and frictions of *Caring Companion* and the affordances revealed the engaging qualities of the soma extensions in terms of bodily interactions. In what follows, I will first discuss the affordances and frictions of *Caring Companion* and then present the revealed engaging qualities of the soma extension.

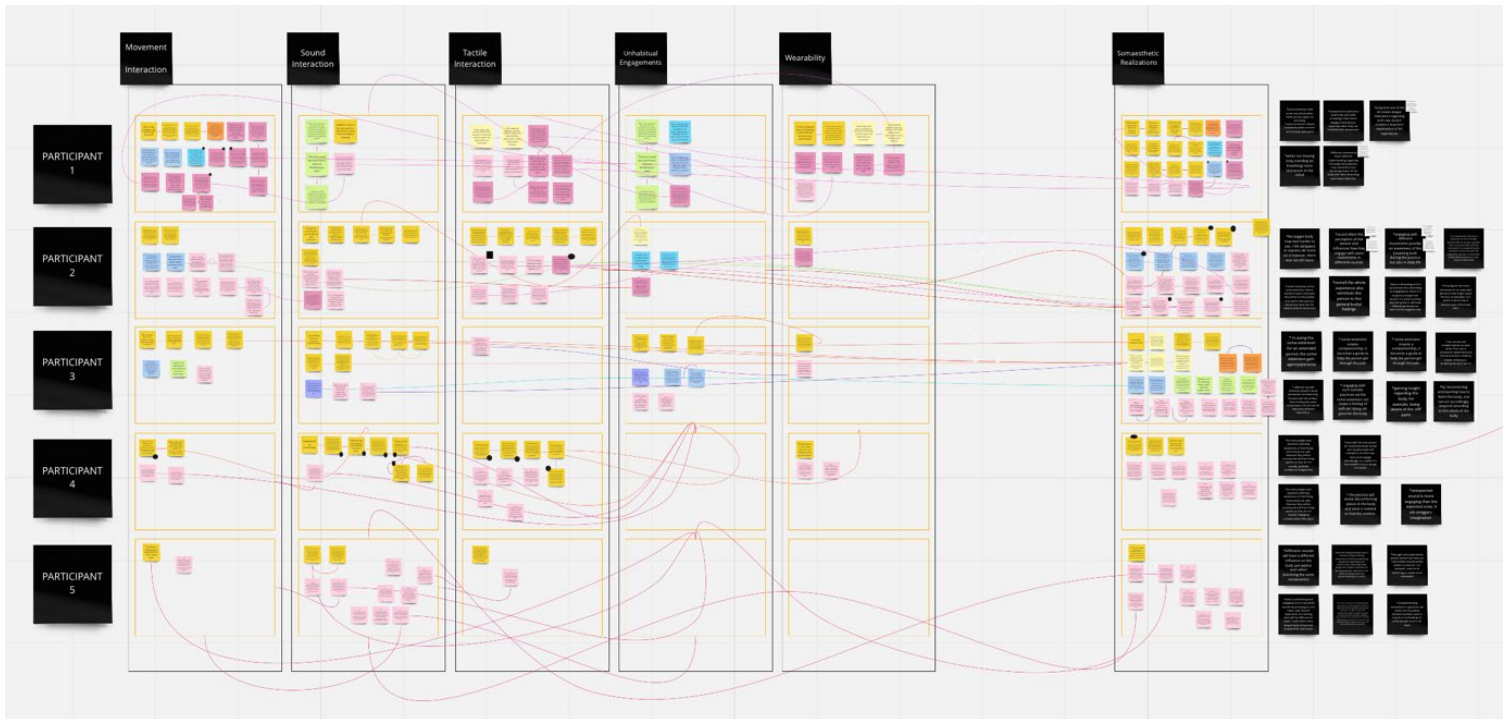


Figure 22. Thematic analysis of the participants' narratives on Miro

The auditory qualities of the soma extension played an essential role in inducing both the agony of and relief from pain. As stated earlier, the soma extension mediated disturbing and pleasant sounds; the former reflects the agony of pain, and the latter the relief from pain. The participants practiced the same yoga sequence with both sounds, moving, feeling, and connecting with their bodies differently. A common experience for all the participants was that the disturbing sound was annoying, albeit at different levels. The disturbing sound was able to mimic the sensation of pain; yet, for Chloe, this created friction as the soma extension became a source of agony for her. On the other hand, the pleasant sound was perceived as calming or neutral. Therefore, as Lily reflected, the sound interaction started with the disturbing tune that is the experience of pain and finishes with the pleasant tune thereby finishing the practice on good terms. I regarded the disturbing and pleasant sound interaction as complementary elements when designing discomforting interactions as they create an interplay between both ends of a pain experience where people can reconnect with their bodies in between.

The tactility of the soma extension created a local awareness of the pain and the feeling of support for going through a painful experience. In experiencing pain, people often touch the pain area to induce the feeling of support on the painful side or as an attempt to relieve tension using massage-like movements. In other words, touching is one of the ways to communicate with pain. When analysing the participants' interactions with the soma extension, two notions were revealed regarding tactility; one was tactile support and the other was tactile focus. Tactile support suggested that close-to-body artefacts can be helpful for people going through discomforting experiences by inducing the feeling of not being alone in this painful journey. In addition, tactile focus can help people to focus their minds on the activity that they will start for their own discomfort; that is, wearing the soma extension to practice the yoga sequence signals the start of the activity. Touch and pain are considered complementary sensations in terms of grounding one's awareness of bodily experiences (Vignemont, 2017). Accordingly, wearing the soma extension on the place of their pain guided the participants' conscious awareness of this area and spreads

their somaesthetic awareness originating from the pain point throughout their bodies. On the other hand, the tactility of the soma extension also created some irritation for the participants, especially in the beginning of their experiences. Until they found a comfortable way of wearing the soma extension on the place of their pain the ambiguity of the wearability of it was challenging. Hence, while designing ambiguous artefacts for people to wear freely, ease of use and provision of some guidelines should also be considered.

While analysing the affordances and frictions of the soma extension, I could not disregard the reflection tools included in each cultural probe kit and used in every engagement with the soma extension. Such reflection tools required time that was not easy to find in the flow of daily life. They were an essential part of the kit for two reasons: 1) they were data collection tools for me to access the participants' felt experiences, and 2) reflection is an important part of self-realisation, and only through reflection can one uncover the hidden dimension of felt experiences. In the account of phenomenology, humans make sense of the world through their bodily interactions (Merleau-Ponty, 2002; Sheets-Johnstone, 1979); however, bodily knowledge is a pre-conscious knowledge (Gallagher, 1986) that can become explicit through reflecting upon it. Reflection is considered a way of knowing and opening the metaphorical gift of pain to turn it into a transformational experience (Hovey, 2018). Therefore, I argue for reflection as a crucial part of somaesthetic awareness. For instance, even though Chloe found the soma extension annoying, she considered writing journal entries as the meditative self-practice. In that regard, the *Caring Companion* kit supported people's somaesthetic unfolding, providing them a space for reflecting upon their experiences and enabling them to see how their bodily sensations and perceptions were changing.

Finally, the analysis revealed some keywords that provide insight into how a soma extension might afford engaging interactions. I employed visual narrative analysis to combine the visual data with the revealed keywords and crafted a visual story accommodated by textual references that illustrate otherwise hidden aspects of the felt experiences. As a result, five notions were generated: 1) companionship, 2) improvisation, 3) resonating with the discomfort, 4) temporality of bodily experiences, and 5) transferring somatic insights into daily life (Figure 23). Hazel described her relationship with the soma extension as a 'companionship' referring to the soma extension as a 'cute animal'; Ava mentioned that practicing yoga with the soma extension was different to a normal yoga practice because it signals the start of something. Hence, the soma extension acted as a supporting companion for engaging with the soma. Regarding improvisation, Hazel mentioned that she took an interpretive approach to the slow walking part of the yoga sequence, and rather than mimicking my movements on the video she moved as if she was dancing. This suggests that in addition to choreographed movements, improvisational flexibility may help people's creative kinesthetic unfolding. In addition, the discomforting qualities of the artefact created a place for engaging with the body; for instance, Olivia was able to find relief from daily worries and focus on the practice through the sound of creaking wooden floors that matched her cracking ankles, and the disturbing squeaky sound of the soma extension. All the participants realised how pain was manifesting itself differently every day and referred to the temporal and changing qualities of somatic experiences. Lastly, Olivia, Lily, and Hazel applied the movements or breathing exercises that they learned via *Caring Companion* to their daily life – integrating the stretching movement of the yoga sequence into their exercise routine. In addition, these notions were informed by the three concepts generated in the first case study (see Chapter 3, Section 3.3.1.). For instance, companionship and resonating with the discomfort constituted the concept of materiality. It was the materiality of the soma extension that induced the feeling of a caring companion; it was the auditory and tactile qualities of the soma extension that corresponded with people's pain experiences. On the other hand, improvisation carried the concept of synchronisation with the body; it was through the harmonious interaction modalities we could support improvisational bodily engagement. Lastly, transferring somatic insights into daily life considered adopting the concept of

mindful engagement with pain as an everyday practice. To conclude, these five notions reflected how the participants interacted somaesthetically with *Caring Companion* and unveiled the qualities applicable to designing engaging soma extensions. The next section will show how I used these notions to create design strategies for designing soma extensions.



Figure 23. Visual and textual collage reflecting the affordances of *Caring Companion* based on the participant narratives of living with *Caring Companion*. Illustration by Arife Dila Demir

4.5.2. Four Design Strategies for Creating Engaging Soma Extensions

As discussed previously, I formalised four design strategies informed by the notions that emerged within the participant narratives that illustrated the affordances of *Caring Companion* in relation to facilitating engaging bodily interactions. Consequently, I offer these generative design strategies for use when designing soma extensions to support better engaging bodily experiences. Below I discuss each strategy in detail.

Building Companionship: In dealing with agonising experiences, people often feel alone and unheard. The notion of building companionship can induce the feeling of togetherness that encourages people to go through discomfort experiences. The feeling of togetherness may maintain somatic support for people guiding them to engage with their bodies and discomforts to develop their caring-attentive somaesthetic practices. “In the isolation of pain, even the most uncompromising advocate of individualism might suddenly prefer a realm populated by companions, however imaginary and safely subordinate” (Scarry, 1985, p. 11). This companionship can be perceived as a living being, like a ‘cute animal’ as Hazel expressed, or as a ‘thing’ as Ava felt. In addition, having a companion may also set people’s minds in a different state, to maintain their focus but open to bodily sensations. Making a formal beginning to such practices is considered a way to consciously and non-habitually attend to mundane bodily movements (Sheets-Johnstone, 2011). Wearing the soma extension for the movement practice indicated a formal beginning for Ava. Inspired by her reflection, I suggest using close-to-body tactile indicative companions to attend to the body and support the concentration on the somatic activity. Finally, in creating the feeling of togetherness, I highlight tactility and synchronous feedback as important design features of the close-to-body artefacts. Touch is regarded as relevant in encouraging and enhancing comfort for patients when the discomfort becomes agonising (Morse et al., 1994). Through designing artefacts that are close to the skin, and to the body, a physical presence of a supportive being or thing can be created. On the other hand, synchronisation between the interaction feedback and the body is essential to create the feeling of unity between the body and the artefact. If synchronisation is not well tuned with the body, the wearer will not feel one with the artefact and the artefact will rather be perceived as a disturbing other rather than a caring companion.

Unveiling the Discomfort: In soma design and bodily interaction design, engaging with various movements and practices is suggested to break the habitual use of the body for somatic realisations (Loke & Robertson, 2013; Wilde, 2011b). The first case study, *Squeaky/Pain*, contributed new insights into the concept of non-habitual engagements that create disturbing experiences in relation to the bodily discomfort in question and mimic its qualities through sound (see Chapter 3, Section 3.4.). In *Caring Companion*, kinesthetic engagements were one way to break the habitual way of moving with the body as well as using disturbing and relieving sounds as implemented in *Squeaky/Pain*. With this second strategy, I suggest deliberately unveiling the discomfort in the designed artefacts to break the habitual relationship of bodies with their bodily discomforts, pain. I discuss that explicated manifestations of bodily discomfort create an unavoidable encounter with it that leads to new connections and perceptions regarding those experiences. To explicate the discomfort, I offer the use of sound in collaboration with unusual kinesthetic explorations. Auditory cues can influence our body perception in terms of movement possibilities, the materiality of the body, the shape and form of the body etc. (Stanton & Spence, 2020). The possibilities of pleasant sounds to facilitate health and annoying sounds to impede health by influencing the state of mind has been explored in the context of cognitive science (Andringa & Lanser, 2013). The use of sound to mimic the qualities of pain may promote better engaging interactions with the soma extensions. When designing the sound for close-to-body artefacts, designers can be inspired by somatic explorations. For

instance, in this dissertation using sound emerged in the first case study, *Squeaky/Pain*, where I studied my chronic pain and realised the squeaky sounds arose from the pain area as I moved (Demir, Ninkulrat, et al., 2022). I invite designers who are working with close-to-body interactions in the context of discomforting experiences to explicate the discomfort. To do this, they can use different sensory stimuli inspired by the sensations that may emerge in their somatic explorations.

On the other hand, unveiling the discomfort in the design creates unexpected bodily encounters that bring attention to it. Discomfort brings attention to the bodily states and the bodies' relation to the world. Somaesthetic awareness of discomfort may lead to an inquiry into the discomfort and the body's relationship with it (Tschaep, 2021). Accordingly, purposefully unveiling the discomfort may call conscious attention that leads to a bodily inquiry which is a journey towards somaesthetic awareness. Finally, to unveil the discomfort in the design we must consider applying both the disturbing and relieving qualities of the discomforting experience in question (and everything in between) to our designed artefacts. These two ends are complementary, and the qualities in between provide a rich insight into the discomforting phenomenon. In translating these different qualities into our interactive artefacts, we can design interactions that will support the experience of being in a diseased and eased body and being in between.

Creating a Room for Improvisation: In the account of bodily interactions, I regard improvisation as an awareness practice where people extend their sensory consciousness allowing new information to become available to the moving body. In improvisation, people attune their bodily experiences in each moment to respond to their somas, thus moving and becoming anew. When designing close-to-body artefacts, designers choreograph some movements for the users through their designs. To mediate non-habitual bodily interactions, guiding users to perform certain movements or gestures can be useful if it is not too strict. In doing so, designers can encourage people to find different ways of moving, enlarging their repertoire of what *I can* (Sheets-Johnstone, 2011) and enhancing their engagement with the artefacts. In *Caring Companion*, the slow walking part of the yoga sequence allowed participants to interpret the action and improvise. As the disturbing sound provided a rhythm and triggered participant imagination by being non-habitual it was more engaging to move than the second meditative sound which was found to be like background music. Here I weave the second strategy unveiling the discomfort with designing room for improvisation and I suggest employing unexpected, imagination-triggering elements to induce the bodily improvisation of people with the artefacts.

Supporting Somatic Engagements in Daily Life: Somaesthetics criticises the philosophical discourse of the body due to its lack of pragmatic orientation that does not support people in converting its ideals into an enhanced somatic practice (Shusterman, 1997). In adopting somaesthetic ideals, when designing for somaesthetic awareness, we aim for the heightened somatic consciousness that emerges through interaction with the artefacts and will expand into daily life. In other words, through the soma design artefacts, designers aim to not only augment somaesthetic awareness when the artefacts are in use but also transfer the somatic insight into daily life (Höök, 2018; Ståhl, Balaam, Comber, et al., 2022). Only then will people be able to cultivate self-caring practices and take actual actions for and with the body. In interacting with soma design artefacts, people may gain conceptual somatic insights, for instance, by moving non-habitually they can be attuned to their bodily experiences, capabilities, and different sensations, or notice how they feel in their bodies connected to their way of living (e.g., their eating habits, stress triggers, etc). By engaging with such artefacts, they would be able to harvest their caring practices. However, I suggest that designers should include concrete and practical elements in their designs that the users can directly utilise in their daily lives. For instance, in *Caring Companion*, yoga movements were the practical elements of the designed interaction, and in finding relief through these

movements, some participants decided to add them to their exercise routines after their participation in the study.

4.5.3. Three Levels of the Somaesthetic Awareness of Chronic Pain

I consider the relationship between the body and chronic pain as entangled, where the pain is the definitive notion of what it means to have a bodily existence in the world for the chronic pain sufferer. In the experience of illness, the body becomes the ‘theme of existence’ that disrupts people’s engagement with the world, and thus, how they give meaning and the way the world gives meaning back to them (Morse et al., 1994). In the case of chronic pain, healing starts with the acceptance of this disrupting phenomenon rather than expecting its removal (Hovey et al., 2018) to allow for change in the meaning of pain experiences; that is, the cultivation of a new bodily understanding and ways of being in relation to pain that somaesthetically engages with the pain. Consequently, I interpret the melioristic approach of somaesthetics as ‘becoming with’ instead of ‘improving’ and design for people to become with their chronic pains, accepting their messy changing bodies and negotiating new ways of living. In other words, I aim to build a reciprocal relationship between the body and pain.

I consider somaesthetics not merely as a single layer phenomenon but rather a multi-layered experience where the somatic awareness of bodies in pain fluctuates in between. In defining this multi-layered understanding I adopt the notion of correspondence (Ingold, 2017), the phenomenology of comfort (Morse et al., 1994), and comfort care theories (Botlorff, 1991; Coelho et al., 2016; Kolcaba, 1992, 1995). Correspondence is a process by which beings or things respond to one another overtime (Ingold, 2017). I regard correspondence as an intimate and sincere communication of the body and pain; that is, cultivating a somaesthetic awareness. In addition, emerging from patient care in medical settings, comfort care and the phenomenology of comfort inform the somaesthetics of discomfort by providing insights into the lived aspect of illness, discomfort, care and comfort. In experiencing chronic illnesses, comfort is defined as enhancing the comfort levels of patients and supporting them to obtain a life where they can live without being dominated by their discomfort (Morse et al., 1994) and feel the potential to regain control of their bodies (Kolcaba, 1992). Janice M. Morse et al. (1990) define comfort as “a state of embodiment that is beyond awareness, and comfort is best recognised when the patient first leaves the state of discomfort” (p. 190). On the other hand, comfort is not merely easing physical distress, but a holistic somatic approach that considers the lived traces of pain on the experiencing body. In this regard, somatic vulnerability is discussed as an essential notion in comfort care that includes both physical losses and the lack of autonomy that emerges in the experience of illness (Coelho et al., 2016). Based on patient narratives, Morse et al. (1990) formalised nine concepts that represent phenomenological corporeality in relation to comfort. These concepts consider care from identifying the symptoms, triggers, and causes of the illness, learning about the diagnosis to develop an acceptance of the discomfort to be harmonised with the world again (Morse et al., 1994). In other words, comfort in chronic illnesses is not the removal of discomfort but rather enhancement of comfort levels through the recognition of the discomfort and the development of a corresponding relation with the body. Seeking comfort is a process that evolves constantly, where the acceptance of discomfort and the changes it brings to the body is a necessary condition to progress in the search for comfort. Accordingly, I define three levels of somaesthetic awareness that start from being aware of bodily experiences to building a corresponding relationship with the pain where the acceptance of the bodily conditions is the prerequisite of this journey.

The first level is the instrumental awareness of bodily phenomena; that is, being aware of the pain, tension, rigidity. For instance, Olivia came to realise differences in her pain experience and discerned non-flexible painful parts of her body. In addition, Chloe acquired an insight into her mental pains, pains of concentration, and creating time for self-practice. The first level of somaesthetic awareness indicates a

detailed somatic alertness. The second level goes deeper into the understanding of the pain experience, including the needs of the painful body and questioning the habitual use of the body that may increase the discomforting experiences. This is the stage where the person acknowledges what can be done to ease the pain or become new to the pain but takes no action. For example, Hazel mentioned that raising her arm and turning hip positions in the yoga flow eased her tension in the pain area and that she could add those movements to her daily routine. Chloe took the kit to her studio after acknowledging the challenge of finding time to use the *Caring Companion* in her daily life. Having the kit in the studio provided her with a gentle break from her sedentary life while working and made it easier to find time to use the kit. Additionally, Olivia, who already knew that long hours of orchestra practice agitated her pain, started to pay attention to how she carried her instrument and how she sits during orchestra practice that was the third layer of somaesthetic awareness where the body in pain acts upon the needs of the body. The third level of somaesthetic awareness concerns corresponding with the needs of pain and taking the responsibility to act upon it, cultivating self-caring practices. Accordingly, in developing the third level of awareness people can find comfort and relief from pain by taking care of themselves. To care for others – things or beings – we must first let them be and speak to us; care demands responding in kind, hence, correspondence happens out of volition yet with a responsibility of care (Ingold, 2017).

Defining the levels of the somaesthetic awareness of discomfort is my attempt to seek comfort in the existence of discomforting experiences for painful bodies, and so people can find new ways of living and being with their pain. In presenting the three-levelled understandings of the somaesthetics of discomfort, I neither claim that the third level is the ultimate point to reach, nor do I frame somaesthetics as a fixed journey within these three levels. I rather invite people to engage with their troubling bodies, with their neglected pains by making the pain experience non-habitual and to develop new perceptions of pain. In doing so, I also invite them to expand the notion of the somaesthetics of discomfort.

4.6. Summary

In this second case study, to explore *how soma extensions may be designed to promote engaging bodily interactions with people with chronic pain*, I conducted a cultural probe kit study to cultivate other people's pain experiences. I presented the participants' lived experiences with the probe kit through narrative inquiry and applied narrative analysis to explicate insights and meanings of their experiences. I then reflectively engaged with the participants' documentations and narratives discussing the affordances and frictions of *Caring Companion*. From the affordances, I extracted actionable design insights to create better engaging bodily interactions in the context of bodily discomfort through four strategies for designing close-to-bodily interactions for the somaesthetic awareness of chronic pain. These strategies were: 1) building a companionship, 2) unveiling the discomfort, 3) creating a room for improvisation, and 4) supporting somatic engagements in daily life. Hence, I propose these strategies as generative concepts for designing engaging bodily interactions. In addition, the participants' experiences with *Caring Companion* contributed to new understandings of the somaesthetic awareness of bodily discomforts. I formalised three levels of somaesthetic awareness in relation to pain: 1) instrumental awareness of pain areas, 2) the understanding of pain, and 3) corresponding with pain. On the other hand, in working with participant narratives and writing my own autoethnographic interlude, I came to realise that not only does designing the artefacts for pain require a careful approach but working with discomforting bodily narratives of people also requires a caring research practice that goes beyond the consent-based ethical considerations. As discussed, designers who work with first and second-person illness narratives should base their actions on ethical and caring foundations, engaging with everyone who is involved in the research at every stage and ensuring their somatic well-being and comfort as much as possible. Finally, by bringing insights into how engagement with bodily interactions can be designed to promote somaesthetic

awareness and extend somaesthetic understanding, this case study addressed the main research question and the second sub-question. Yet, it revealed the notion of temporality; in other words, that the bodily experiences had a temporal aspect; even in the experience of chronic pain, how pain is manifested in the body changes daily. Therefore, to facilitate the somaesthetic awareness of pain, soma extensions need to address the temporal quality of bodily experiences. By opening up the notion of temporality, *Caring Companion* led to a new inquiry. In the next chapter, I will explore the temporal quality of the pain experience to design a soma extension through the third case study.

CHAPTER 5



Photograph by Kadri Tiganik

5. CASE STUDY 3: PAIN CREATURE

The temporal qualities of bodily experiences refer to how we experience our own bodies change over time. Such experiences include shifts in our bodily awareness and perception as well as changes in intensity, duration, and the qualities of bodily sensations. Pain as a bodily sensation is a temporal experience constituting different qualities that change in the course of time. Chronic pain implies that the body can experience pain anytime, yet when and how is unknown, leaving the person in agonising ambiguity. Whenever pain appears, objective time or *Chronos*, which can be measured by the clock ceases to exist and leaves its place to subjective time, *Kairos*, where the perception of time dilates through the experience of the discomforting event of pain (Brough, 2001; Hovey et al., 2018; Toombs, 1990). Despite the agonising possession of pain, pain constitutes generative and transformational qualities that are revealed when it is given a voice and is listened to. Listening to pain is only possible when the body settles into her experience to live through the embodied sensations within subjective time. Listening to pain leads to an in-depth understanding of the versatile qualities of pain, and the body can correspond with her pain for transformational becomings. Pain communicates its versatile qualities through auditory and textural information. The cultivation of these qualities may inform the materialisation of pain which enables an unusual way of communicating with it and facilitates the somaesthetic awareness of discomfort. In this research, in order to understand how the somaesthetic awareness of chronic pain can be facilitated, *Pain Creature* was created as a soma extension that wove distinct qualities of the chronic pain experience and reflected them in its design. It used pain as a catalyst to change and transform the ways of being and living with pain. This transformational process goes back to the correspondence that happens when the body and pain interact with one another creating a mutual reflective conversation. For this to happen, *Pain Creature* interrupted *Chronos*, making space for *Kairos* to settle into embodied experiences ready for reflection and new becomings.

5.1. Aims of the Third Case Study

In the second case study, *Caring Companion*, I examined *how soma extensions may be designed to promote engaging interactions with people with chronic pain*. In doing so, I formalised five actionable design strategies to be applied to the designing of engaging soma extensions and close-to-body interactions. These strategies were used in designing the third case study, *Pain Creature*. In addition, the second case study revealed temporality and the changing dynamics of pain as essential qualities of this discomforting experience. According to Brian Cutter and Michael Tye (2011, p. 104), “the felt badness of pain comes in degrees. Any adequate account of the painfulness of pain must not only account for the fact that pain is painful, but also for the fact that pain can be painful to different degrees”. Even though chronic pain is woven into the fabric of everyday life, it is not experienced at the same level at every moment of every day. Pain as a temporal object always appears to us now. In the flux of time, now becomes past and future, and in each now, we experience pain with the influence of our past experiences and future fears regarding agony. “Each ‘new now’, is a new phase of the temporal object that we are experiencing, and each ‘past now’ is an elapsed phase of the object, a phase that once was but no longer is now” (Brough, 2001, p. 32). Pain that is experienced at present might constitute different dynamic qualities to the one that has been experienced or will be experienced in the future. This does not mean that previously experienced pain will never re-appear; they will in different moments, perhaps slightly differently or the same but the experiencing body will be altered.

Gudrun Nilsen and Ingunn Elstad (2009) acquire two main themes of pain from a narrative inquiry into patients’ stories of their chronic pain, where the temporality of pain emerged as an essential notion and an episodic structure of pain. The episodic structure of pain encompasses different qualities of the pain

experience, such as pragmatic and transformational aspects of it as well as versatile felt aspects – its softness or severity. The felt aspects of pain provide both the material and conceptual properties of the pain experience and together they form its dynamic changing qualities. When thoroughly articulated, these qualities can be translated into soma extensions that can address the altering dimensions of pain, providing somaesthetically engaging bodily interactions. The main research question of this dissertation is: *How may movement-based interactive textile wearables as soma extensions facilitate the somaesthetic awareness of musculoskeletal chronic pain through mediating explicated interactions of it?* The examination of this question through the first case study revealed how pain can be used as a design material offering tools to elicit and articulate the felt experience of pain, while the second case study provided design strategies to improve the bodily engagement of soma extensions. These case studies approached pain as a temporal experience between agony and relief; yet, the in-between qualities have never been articulated. I, therefore, aimed to explore in the third case study the in-between qualities to inspire the design of soma extensions, by delving into the following sub-question: *How may soma extensions be designed to address the changing needs of the bodies in chronic pain?*

Brough (2001) discusses that while a person may not be available to share his pain or imagination, art affords the expression of the subjective world that is also capable of intersubjective communication while embodying the subjective life. Combining the roles of somatic practitioner-artist-designer-researcher, I employed the first-person research methodology to elicit the dynamic aspects of my chronic pain experience to explore the above stated research question. I cultivated the material and conceptual properties of these dynamic aspects of pain to inform the design of the soma extension through kinesthetic engagements informed by dance improvisation. Through this case study, I presented *Pain Creature* as a soma extension that echoes the changing pain experience that mediates engaging bodily interactions for the somaesthetic awareness of pain. In designing *Pain Creature*, I also cultivated new perceptions of my pain experiences. In what follows, I will first illustrate how my pain journey unfolded during this case study, then unpack the design process of *Pain Creature* and discuss the preliminary results of this case study.

Interlude: Designer's Autoethnographic Reflections of Pain

When I started my PhD journey, the only chronic pain that inhabited my body was musculoskeletal upper body pain that was active on the right side of my body. A year went by, and around the middle of the second year of my doctoral studies, a terribly discomforting experience took over my body. I was not able to eat anything, losing too much weight, always feeling nauseous, and experiencing terrible abdominal pain. I lived with this for six months until I got a diagnosis, and another six months to find a proper treatment that might make life 'normal' again. I was diagnosed with IBS, SIBO, and histamine intolerance, which led to the involuntary reorganisation of my whole life causing struggles. My condition is improved now; however, I still struggle weekly if not daily. The struggles revolve around syncing my body with sequential time, which is measured by clocks, in order to function in this world. These struggles made me pay attention to little details that I would never be aware of. It is amazing how a body free from chronic discomfort is also free from many worries and details that are incredibly essential for the ones living with discomfort.

One of the details that became quite essential to me is how we organise the days, weeks, and months; how we schedule everything using clocks, thinking that all the bodies will be able to put up with it. Time becomes a critically important notion for those living with discomfort, it has such significance in my life. In between the scheduled appointments, I try to prepare my body to function within the scheduled times, which is really really hard and sometimes it is just not possible. One cannot expect to be in total control of the body; being a human, an embodied being, means I am the

body and I need some time (maybe more than some others need) to perform within the sequential time where we work, go to meetings, meet with friends, travel, etc.

So, I see a therapist to deal with my IBS/SIBO stress, and anxiety triggers the physical symptoms and these physical symptoms leave traces in the psychology of a person. Therefore, I am trying to manage my stress as well as alleviate the mental struggles I have in living with this chronic condition. My therapist talks about the acceptance of the chronic condition to become new, to develop new mindful living practices in relation to my condition. She refers to two types of making peace: 1) accepting the situation as a victim, and 2) accepting the situation by making peace. Until this conversation I was thinking that I accepted my situation – except for the times when I have IBS attacks, then I am down to feeling horrible about everything, hence, not surprisingly I realised that I accepted the situation as a victim. I was not enjoying my new way of living that was forced upon me. This whole situation (me struggling with IBS) made me think about my research and my chronic upper back pain; in the somaesthetics of discomfort, acceptance plays an essential role in starting this mindful sensory aesthetic journey of becoming a new with the discomfort. In my work, the first level of somaesthetics concerns heightening bodily awareness and listening to the body; to mindfully do this, one needs to first accept the pain without victimising herself.

As I wrote in my first autoethnographic reflection (see Chapter 3), a few months before starting my PhD I started to experience upper body chronic pain. Compared with the agony of IBS it was mild; however, it was disturbing enough to ruin the quality of my sleep, it influenced my yoga practice and since I was unable to carry heavy bags (and by heavy, I mean not really all that heavy) it interfered with how I did the groceries and my vacations for which I mostly used my backpack. This was the time when I first had to encounter an involuntary transformation of my life. I mostly struggled with my yoga practice because the positions that were once easy for me were not available anymore, they were causing too much distress and pain in my right neck and shoulder. Of course, not to mention how it influenced my daily mood as it disrupted my sleep. For a while, I fought my pain and even forced my body into these positions thinking that I could continue as if nothing had happened and ignored the pain. Of course, that didn't work at all!!! So, I started to incorporate yoga poses into my practice that helped me to relieve the tension on my right upper back and removed the ones that caused pain. Later, I started to practice the challenging ones slowly by listening to my body, not forcing it to increase the pain but slightly aiming to extend the new boundaries of my body in pain. In addition, I started to cycle and swim which was not challenging my chronic pain. Swimming even helped me to relax. When I saw that after losing my old habits I gained lots of new enjoyable ones (not only in terms of exercise but also in terms of my living practice i.e., arranging my groceries so I don't need to carry heavy things, not going backpacking but different ways of enjoying a vacation), I realised that I had peacefully accepted my upper chronic pain and became new with it through the voluntary transformation of my life.

This transformation took me a long time, almost four years of the PhD period, as my transformation unfolded during my doctoral studies. Now I had first-hand experience of how engaging with pain – and with explicit expressions of pain – helped me to develop somaesthetic awareness by becoming new to my pain and by exploring this phenomenon as my research question. Yet, I know that this process is not easy, and it is not linear; it is a messy, chaotic process with lots of ups and downs and it does not have an endpoint, it is a challenging as well as rewarding life-long journey. I also know that different bodily discomforts require different time and effort to be peacefully accepted for one to start the somaesthetic journey. I had come so far in my journey with upper body chronic pain, but after two and a half years I cannot say the same thing for my IBS/SIBO which I could not even peacefully accept yet!

One final note on becoming new with the body is that one needs time, time that is not scheduled, that is not squeezed in between other appointments, meetings, etc. But a qualitative time that is in between the sequential time, time that pauses everything but the body; it is the time to mindfully attend and engage with the body (and hopefully to be able to transfer this attentiveness to daily life). We all have this time, but it is just not easy to somaesthetically engage with the body in that time; while living with IBS, I spend my hours worrying about it during that time rather than getting into the experience and allowing myself to relax.

Note 1: I am writing this paragraph at the airport sitting close to the gate waiting for my plane and hoping, really really hoping that things won't go bad, I won't have an IBS attack or period pain. I hope that two pills for IBS and 1 pill for period pain will help me get through this journey. I hope that I won't get hungry, so, I won't have to eat the food that I carry with me. Even though I have got my safe food, I cannot be sure that everything will be fine. It is now noon time and I'll be at home late, very late evening, and I know that I'll get hungry. I just wish that it won't happen while I am on the plane; I would be much more relaxed. I'll soon close my computer and do the breathing practice that my therapist taught me. I hope that it will help me to calm down.

Note 2: I just finished my writing, there are only one and a half hours left for my first flight to arrive, then I'll be waiting for my connection which is only a 40-min. flight. Anyway, when I am on my period, I always get hungry more than usual, so, of course, I got hungry on the plane and ate more than half of the food that I took with me and so far I feel okay, it is even kind of empowering to eat and feel okay!

5.2. Design Process

The process of designing *Pain Creature* was unfolded in two phases: 1) somatic exploration, and 2) material exploration. Within these two phases, I adopted *moving through*, *listening to*, and *thinking with pain* as a methodological approach to design with/through/for the pain. In this case study, I aimed to cultivate and elicit multiple dimensions of a chronic pain experience by employing a first-person perspective. Through this subjective inquiry into multiple dimensions of chronic pain, I was able to enhance my bodily sensitivity in relation to the fine nuances of the pain experience that in turn enabled me to create an artefact constituting a dynamic experience of pain.

I started the process of designing *Pain Creature* with an improvisational movement experiment where I moved through my pain in silence by listening to it as a non-habitual bodily engagement. This was the first phase of somatic exploration in which I danced for four consecutive days through the silence, howls, whispers, and textures of my pain; each dance, which lasted about fifteen minutes, revealed peculiarities of my pain experience. Since soma extensions explicate pain through sound and material expressions, I aimed to cultivate the sound and material qualities of different reflections of my pain experience through the improvisational movement experiment. Unlike the previous case studies, I utilised improvisational dance rather than yoga as a somatic exploration method. Yoga can facilitate the bodily awareness of proprioception and breathing and enable the conscious focus on each body part and sensations potentially emerging in the body part in performing well-designed flows of yoga poses. In improvisational dance, body awareness increases as the body forms movements in the spontaneous flow of the moment.

Movements that are created in the moment through dance improvisation are derived from the endless variable forms that may be generated through the body. In dance, the inauguration of each movement contributes to the creative open-mindedness of the dynamic flow of movement (Sheets-Johnstone, 2012). Through improvisation, the dancer dynamically creates shapes, forms, and forces as the affordances of the body in motion and simultaneously perceives them in an ongoing process of creation (Kronsted &

Gallagher, 2021). This is an active loop of perception and action; the movements are created through the body that locomotes in a creative engagement with the affordances found in the body and the surroundings. My improvisational movement experiment was realised through my engagement with the affordances found in my body in relation to my pain. In dance, metaphors are enacted; they are brought to life as bodily forms, shapes, and forces (Kronsted & Gallagher, 2021), where, through the qualities of the movement, stories are generated (Sheets-Johnstone, 2012). In moving through my pain, I enacted the story of my pain and its different qualities. In doing so, I cultivated the versatile aspects of my pain experience that were later reflected in the design of the soma extension.

My improvisational movement experiment was inspired by the contemporary urban dance classes that I had participated in through 2018–2019; and the GAGA method that I had practiced via online classes in 2020–2021. In both, I had learnt how to initiate movement by listening to the specific body parts; for instance, focusing on the right wrist and exploring how it moves the whole body. Based on what I had learnt in these dance classes, during the four-day movement experiment, I started my movements by focusing on my right upper back, specifically my right shoulder, neck, and shoulder blades, which are my painful areas, and let the rest of my body follow the movements initiated from my pain areas expressing the painful sensations that dwell in my body. Sheets-Johnstone (2012) discusses that there are ceaseless amounts of initiating the same movement from different body parts; for example, inaugurating an arm raise from the shoulder, elbow, wrist, or fingers. Similarly, there are endless possibilities of movement that may emerge within the same body parts. Every day the movements started from the pain areas, yet every day different forms, shapes, and forces were incarnated as pain moved and danced through my body manifesting its many dimensions. In improvising through my pain, I explored the materiality of my pain and my bodily existence, specifically by experiencing the tactile and auditory qualities of my corporeal being.

After each practice I noted down keywords informed by my movement experiment (Figure 24). These keywords represented the material and sound qualities of different expressions of my pain. For instance, on my first day, I experienced warm and heavy pain; my shoulder felt too heavy like a burden that is rough as a material quality. On the same day, the heaviness that was also reflected as warmth invited soft touches and gentle movements, so that I danced through touching my body, especially my pain areas. Warm touch, heavy, rough, gentle, and heat were the keywords of this day. The second day revealed the sensations of connection and deep stretch; the materiality of my pain area and my whole body was vibrantly available for my conscious experience; I felt the sounds of my blood, veins, tissues, muscles, and bones; I felt the strong connection with all my body parts. Therefore, strong flesh, connection via stretch, connected tissues, and contact became my keywords for the second day. On the third day when I was moving, I felt like my shoulder blades were like layers of earth that were moving as I was moving through my pain and generating the sounds of tectonic plates that became one of my pain keywords. On my last day, I felt the flowy, wavy movements but also felt disconnected, empty, and meaningless; these sensations formed my keywords of the fourth day. In addition, the keywords highlighted the complexity and temporality of the pain experiences by eliciting various qualities of pain even on the same day.



Figure 24. From left to right the visual shows the keywords noted from day one to day four. Photograph and Illustration by Arife Dila Demir

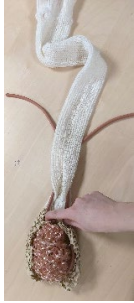
Through these keywords, I textually documented the felt sensations of my movement experiment. In addition, I video-recorded the improvisational movement experiment to document the temporal and dynamic aspects of my lived experience. Video documentation is discussed as a tool to tackle the challenges of representing the dynamic temporal nature of the moving body (Loke & Robertson, 2010). Sheets-Johnstone (2012, p. 53) writes that the moving has a ‘felt bodily dynamic’ whereas the viewer has a ‘visual bodily dynamic’, yet the qualitative dynamics of the dance are essentially the same; what is kinesthetically felt, visually perceived as the same. Accordingly, the video recordings helped me to recall the bodily dynamics of what was once a felt bodily dynamic for me to later elicit my bodily experiences in the design process. After completing the improvisational movement experiment, I transitioned to thinking with pain to elicit my felt experience of moving through and listening to pain, which is the meta-level conceptual engagement with my reflections of pain. For the conceptual engagement with pain, I re-watched my videos while reminding myself of the keywords and extracted still images from my videos that resonate with the keywords. I drew body maps on the still images to highlight the visual expressions of the pain, the keywords synthesising visual and written expressions of my felt experience. Such methods enabled me to communicate the inarticulable aspects of my lived experiences and to aid the meaning-making process. By thinking with my pain, I generated the final six pain dimensions to translate into the design of the soma extension, *Pain Creature* (Figure 25). These dimensions were 1) *Burden*, 2) *Tectonic Plates*, 3) *Waves*, 4) *Warm Touch*, 5) *Flesh*, and 6) *Empty*.



Figure 25. Six temporal pain dimensions revealed in the somatic exploration phase by moving through, listening to and thinking with pain. Illustration by Arife Dila Demir

Generating these six pain dimensions was the final step of the somatic exploration phase that led to the beginning of the second phase, which is about material exploration. In this phase, the aim was to translate the pain dimensions into the dynamic components of *Pain Creature* that constituted different tactile and auditory material qualities. For the creation of the soma extension, I collaborated with a sound designer who worked on the sound design and technical development of the artefact. As shown in Table 5, I started to ideate the six pain dimensions through using material qualities that include auditory and tactile expressions. In this phase, my collaborator was actively involved in the process as the choice of technical components influenced my textile material decisions. For example, we used piezo sensors to sense the movement which also worked as a microphone meaning that it was able to record the sound of the moving materials and play it back as part of the designed sounds. The material decisions were also influenced by the sound qualities, and we experimented with the materials and techniques that may create sensations that resonate with the pain dimensions.

Table 5. The thinking with pain phase, where I ideated on the possible material, tactile and auditory qualities of each pain dimension

<i>Burden</i>	<i>Tectonic Plates</i>	<i>Waves</i>	<i>Warm Touch</i>	<i>Flesh</i>	<i>Empty</i>
Paper yarn for roughness, cables for heaviness, tight knitted structure that is hard to stretch to give the feeling of heaviness, agonising heavy sound	Earth tones, sparkling, earth sounds	Soft loose knit structure and explorative shapes and explorative sound	Soft loose knit, inviting to touch, hairy and warm, warming comforting sound	Ripped out flesh visual, lumpy look, bloody/watery sound with a feeling of pulling	Sound of the flesh and bones of my pain location
					

The approach of moving through, listening to, and thinking with pain was adopted for the process of making *Pain Creature* and consisted of various material experiments. As I was creating material samples according to Table 5, I was moving with the materials to explore whether they mediate the respective pain dimensions while listening to the designed sounds and integrating them into the material samples. In thinking with pain, I reflected on my experience of moving through and listening to pain to evaluate the material engagements and decide on the final forms of each pain component. In the technical development of the artefact, the sound designer and I realised that the complexity of the sound design was taking up too much memory space on the microcontroller causing glitches. For this reason, we needed to eliminate one of the pain components from the artefact to maintain sound quality and smooth interaction with the soma extension. I chose to eliminate the sixth component, *Empty*, the invisible component that aimed to mediate the sheer sound of the painful area in the body. Since this dissertation aimed to provide externalised interactions of pain through both sound and materials, I decided to continue solely with the external pain components to maintain the integrity of the study.

Figure 26 illustrates the final design of each pain dimension of *Pain Creature*. The body of *Burden* was tightly knitted with stretchable yarns; its length was determined to be rather short for a challenging interaction that mediated a sensation of hardness and heaviness. The end of this component was knitted with paper yarns where a heavy cable was integrated into the structure for the piezo sensor to work as a microphone recording the sound of the material. The recorded sounds of the paper structure were played

back in addition to the designed sound. *Flesh* was knitted with vibrant red and pinkish yarn representing the tissues, muscles, and blood; it has lumps coming out of the knitted structure. The length of *Flesh* supported multiple stretching movements that can be performed and felt through the integration of whole bodily movements. *Tectonic Plates* consisted of multiple knitted cord-like elements that were braided; at the end of this structure, there is a small bag containing lentils as well as the piezo sensor. In *Tectonic Plates*, lentils were used to support the sound design as the sensor recorded and played back the sound of the moving lentils. *Waves* was designed as long soft tubes that have another tube-like structure attached to the end. *Waves* was one of the longest components that invited the feet and legs to entangle with the artefact; the sound design and the ambiguous shape of the artefact aimed at flow-like exploratory engagements. Finally, *Warm Touch* was designed as a long, big hairy component inviting soft touch, mediating warmth due to the material qualities of the felt. The sound design of *Warm Touch* focused on evoking comforting sensations.



Figure 26. Final design of *Pain Creature* with its five different components. Photograph by Kadri Tiganik and Illustration by Arife Dila Demir

In addition to this dynamic process of designing with/through/for the pain, the process of making *Pain Creature* was informed by the four design strategies for promoting engaging interactions that emerged in the second case study: 1) building a companionship; 2) unveiling the discomfort; 3) creating a room for improvisation; and 4) supporting somatic engagements in daily life. The first strategy suggested the need for a companion who can be there for the one in pain during the agonising experiences. This strategy was transferred as supporting the feeling of the warmth of a hug through the design of a soma extension that

fits perfectly to the body creating the sensation of a tight warm hug. The second strategy was adopted by exposing the multiple qualities of pain through the revealed five dimensions and enabling the wearer to interact with the dimensions of pain according to her choice. The third dimension was embraced to promote somatic engagements in daily life by sensitising people to their bodily experiences through kinesthetic-tactile and audio interactions with pain. Finally, the fourth strategy was applied to facilitate creative engagements with the bodily movements through listening to the felt bodily sensations.

To sum up, as a result of the somatic and material exploration phases, *Pain Creature* (Figure 27) came to be a soma extension that represents various dimensions of the chronic pain experience and facilitates somaesthetic awareness. *Pain Creature* represented the five changing dimensions of the chronic pain experience that were reflected as five tangible components on the artefact with different tactile and auditory qualities. The artefact provided a kinesthetic-touch-audio interaction, enabling the body to communicate with the multiple dimensions of the pain experience through augmenting bodily sensations. While each component was permanently placed on the artefact, they were connected to the microcontroller that enabled digital interaction via mini jack ports that can also be disconnected. Hence, the wearer was able to choose which component she would like to engage with according to her pain experience. To explore the affordances of *Pain Creature* in relation to somaesthetics and how it addresses the changing bodily experiences I conducted a test where I lived with *Pain Creature* for a week.



Figure 27. I am moving with *Pain Creature*. Photograph by Kadri Tiganik

5.3. Narrative of Living with *Pain Creature*

As mentioned in the previous section, to analyse the affordances of *Pain Creature*, I conducted a first-person perspective test, where I lived with the soma extension for a week to see how it unfolded in my daily flow, rather than setting up a test environment. I had a week to engage with the soma extension any time I felt the need to use it. The length of each use was also flexible, depending on my bodily sensations. In addition, I was free to choose which components I wanted to engage with. In total, I used the artefact three times in various combinations of pain components, for different durations. Each use was triggered by different needs that emerged within my body in my daily flow. To capture my experience, I video-recorded myself living with *Pain Creature* and wrote about my felt sensations after each experience. After finishing the week of living with *Pain Creature*, I first re-read my journal entries and watched the videos to extract still images from the video recordings that reflected my writings. In doing so, I created collages that represent my experience of living with *Pain Creature*. In what follows, I will first illustrate each day with *Pain Creature*, portraying my narrative through my journal writings and visual collages and then present the analysis of me living with *Pain Creature*. When questioning the meaning of life with pain, emerging conversations increase the narrativity revealing stories that include sadness and isolation as well as courage, generosity, and the support of others. Hence, in presenting my journal entries I expose my pain narrative that comprises the story of me finding new ways of living with pain. The following journal entries included direct quotes from my journal as well as re-written yet non-fictional elements to depict my story of living and becoming with *Pain Creature*.

Day 1 - January 19 (Figure 28)

In the afternoon, after spending my morning in front of the computer probably in some poor posture, I decided to wear the soma extension. Our encounter lasted fifteen minutes of improvisational movements. I did not feel any particular pain sensation, but I wanted an excuse to move my body. I kept all the arms connected to experience the different aspects of pain. It worked quite interestingly. Without touching any arms, I moved and swayed side to side and, as I performed subtle bodily gestures, I heard the sounds of different pains at the same time, some were more powerful than others, yet all influenced how I continued my performative act. The way I interacted with it opened up various possibilities that support creative improvisational engagements. One-by-one each interaction with each arm facilitated different emotions and movements; with some I wanted to stay longer. For example, I wanted to remain in contact with the *Warm Touch* that perhaps reminded me of the lack of a gentle touch – do I long for it? The sensation of *Warm Touch* revealed the need for miraculous physical touch that may ease the pain and bring comfort, touch became a sensation that may dissolve pain. I felt that *Waves* represented the smooth daily flow that vibrates within the body and is not realised until the pain disrupts it. So, I wrote, “[p]ain is like a disruption, disruption of smooth wavy embodied existences, claims immediate attention, and requires to be taken care of”. I realised how agonising pain can be, you feel that it is there, and you can reach it with your fingertip but cannot grasp it for removal. Yet, I felt like agony can be playful as well, when the removal of pain is not possible by touch, it might be possible by moving the body. Or as I noted in my journal “Is it just an illusion?” Through *Flesh* I felt my corporeal existence vibrant and lively. The soma is raw; it is sensations, flesh, bones, water, and blood..... It is strong, so you can hold on to it, you need to really engage with it with your whole body, pull it, stretch it... and feel the watery flesh moving with your body.



Figure 28. Still images of the interaction with the *Pain Creature* from the first day, highlighting the performed movements. Illustration by Arife Dila Demir

Day 2 - January 20 (Figure 29)

It was late afternoon, I was sitting on the sofa reading for work, which I found a bit boring, then I decided to wear the soma extension, longing to calm down and relax, not from pain but from the tiredness of the flu. So, I wore *Pain Creature* using only *Warm Touch* and *Waves* over an hour of explorative and from time-to-time silent interaction. I realised that sometimes my body just gets too silent, just stays still without even a little movement. I realised that it was because sometimes for some minutes I did not hear any sound coming from *Pain Creature*. It was a little challenging to find a way to comfortably sit on the sofa with *Pain Creature* on my back, but eventually I found an easy way to sit with it. I felt like sitting with a second body, a companion, which is also my body. After a while, it became one with my back, one with my whole body. Due to my sickness, I did not really have much energy to move but doing soft circular moves helped me to regain some energy. It felt only natural to be with *Pain Creature*. To me sitting still for a long time is almost impossible, I always move and do silly things; I did the same with *Pain Creature* only this time I had an orchestra with me. Or more like a conductor that orchestrated my movements with soothing sounds. I did not wear *Pain Creature* to resonate with my pain today although I was feeling a bit tense in my right shoulder, I built the sofa myself and I am chilling on it today. Anyway, I realised being, melting and moving with *Pain Creature* eased the tension in my right shoulder.

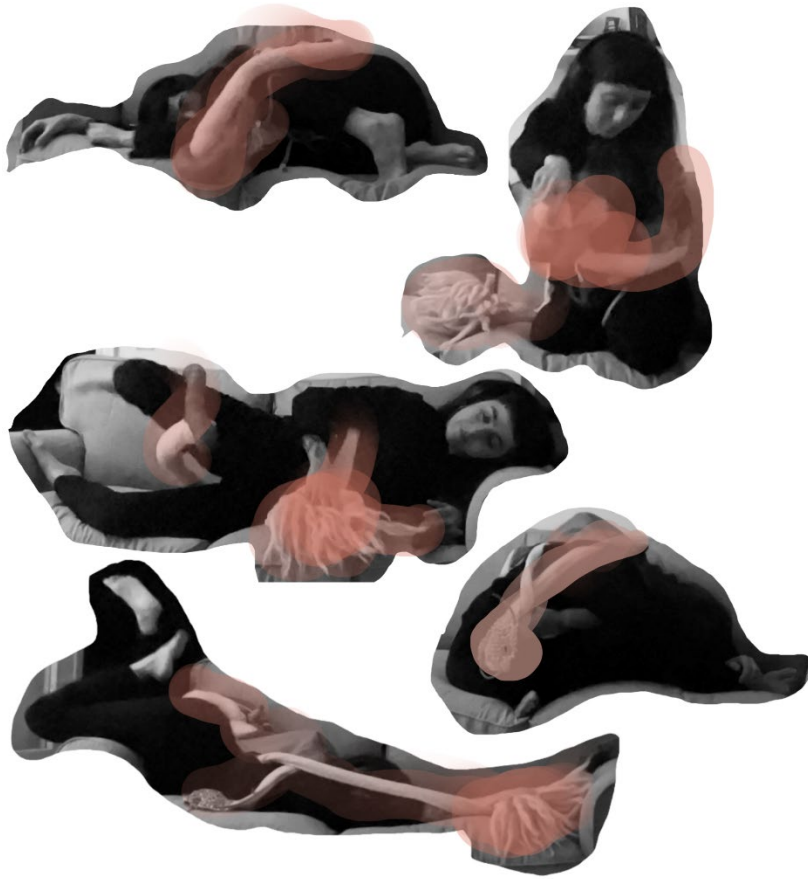


Figure 29. Still images of the interaction with Pain Creature from the second day, highlighting the performed movements. Illustration by Arife Dila Demir

Day 3 - January 22 (Figure 30)

It was early morning, and during my yoga practice I felt pain in my right shoulder and on the right side of my neck. To be clear, it was not agonising but there was a powerful sensation of heaviness and fullness. These sensations created the urge to do a deep stretch where all the tissues, muscles and bones can participate, so, I can get a good feel of the whole bodily connection. Therefore, I wore *Pain Creature* to feel *Flesh*, thinking that a good stretch might ease the tension. I performed some stretches with *Flesh* that helped me to even feel the deeper sensations of each movement; subtle implicit motions of my body were available to my perception through it. I am my body; however, when moving with *Flesh* my inner bodily sensations became the other that helped and guided me through the process of deep relaxation. Yet, this otherness was not perceived as foreign or alien, the other was also me but once this less silent other became very local, it claimed a bigger space in my perception and brought a softness to this space that it inhabited. Later, I wanted to experiment with *Tectonic Plates*, *Heavy* and *Flesh* all together. *Burden* was agonising, it always reminded me of the disruption of pain, *Tectonic Plates* were hopeful even if it was located on the disturbing side of my pain experience because I felt like by moving with my whole body in certain ways, I can move the tectonic plates to where they should be, to where I can find peace. These three formed an expressive orchestra of painfulness where I felt like I could explore different manifestations of pain and how to communicate and live through and with them.

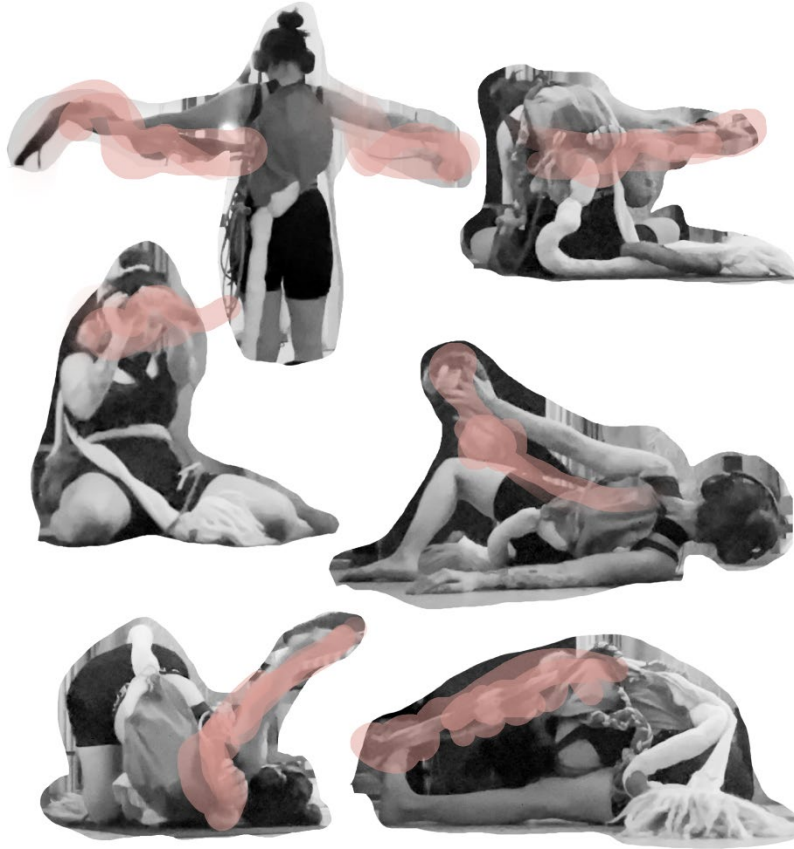


Figure 30. Still images of the interaction with *Pain Creature* from the third day, highlighting the performed movements. Illustration by Arife Dila Demir

Through these three journal entries, I portrayed my encounter with *Pain Creature*, which unfolded my experience of pain on multiple levels. Living with *Pain Creature* became an experience of living with the physical manifestation of pain with which I can communicate, and through whom I can get in touch with my body.

5.4. Reflections on *Pain Creature*

Here I will provide my reflections on *Pain Creature* in five sections based on the analysis of the design process and my narratives of living with *Pain Creature*. In the first section, I will discuss the affordances and frictions of the soma extension. In the second section I will review the methodology I applied in the design process of this third case study to design with/for/through pain. In the third section, I will introduce the reformed versions of the design strategies that had emerged in the second case study. Then I will introduce the notion of *Kairos* through which I extend my understanding of somaesthetics as a theoretical insight. Finally, I will discuss *Pain Creature* as a collection of sounds and tactile textures that enables the non-verbal communication of pain that is the artefact.

5.4.1. Affordances and Frictions of Pain Creature

I analysed my living with *Pain Creature* and shared my reflections on this experience by focusing on the soma extension's affordances and frictions. To do this, I interpreted my journal writings and video recordings to delve into the meanings and peculiarities of my experience. My approach was inspired by

interpretive phenomenology and hermeneutics, but I did not employ any strict method. Rather, I engaged with my visual and textual documentation through a dialogical conversation. Interpretive phenomenology regards humans as embodied and situated beings exploring how the experience of a person unfolds in a given situation and context; it aims to articulate the particularities of the given experience (Given, 2008). Accordingly, my analysis articulated the unique nuances that emerged in my experience rather than aiming to generalise the affordances and frictions of *Pain Creature*. I illustrated one of the many possibilities of *Pain Creature* to resonate and correspond to a body in pain. According to Hovey et al. (2018), hermeneutics as a reflective practice does not search for a cure but rather explores how life is and might become; hence, it can aid people to alter their perception of pain alleviation from physically removing pain to learning to live better lives with pain. In other words, it supported transformational somaesthetic becomings. The analysis of my living with *Pain Creature* revealed the unique characteristics of my experience and put me into a reflective conversation with my pain.

The movements manifested through improvisation have intentional meanings through which the moving body almost forms a story, which is even more conspicuous when two or more dancers improvise together (Merritt, 2015). My engagements with *Pain Creature* were the improvisation of two bodies that participated in the creation of a dynamic movement flow that constitutes corporeal meanings in relation to pain. I, as a body, and *Pain Creature* together formed the dance of pain corresponding with each other, reflecting the meanings that emerged via the body in pain. Affordances of *Pain Creature* brought forth the meanings through the movements that include the action capabilities between my body and *Pain Creature* itself. An affordance is normally defined as the possibility for action as it is directly perceived in an object. In improvisation, the dancer acts upon her kinesthetic unfolding that enables the next movement to emerge, through which the body generates affordances as well as explores those affordances (Kronsted & Gallagher, 2021). In other words, the moving body constantly creates new kinesthetic possibilities by exploring the movements that it creates concerning the things and beings with which it interacts.

In using *Pain Creature*, I performed movements that brought forth new affordances from *Pain Creature* that in return shaped my actions in a fluid loop of transformational dance. This transformational dance contributed to my somaesthetic journey of becoming with pain. In my somaesthetic journey, I came to realise that pain might never be removed, hence accepting this possibility is essential to developing new practices of being and living with it. The analogy of the gift of chronic pain is to acknowledge that the removal of pain may never happen. The unwrapping of this gift can be quite elusive, emotionally painful and devastating. “This self-reflective gift is not a physical gift that one holds, shakes, and admires. It is found deep within us and our identity and uncovered through our thinking, learning, and personal agency” (Hovey, 2018, p. 11). In living with *Pain Creature*, I did not seek alleviation but corresponded with my pain as a self-regulative act that helped me to be mindful of myself, my body in pain. In doing so, I moved forward in my somaesthetic journey, from acknowledging my pain to cultivating caring practices; that is, providing the time and space that my body needs.

I used *Pain Creature* three times a week where each use was driven by different bodily needs. For instance, on the first day, I was longing for movement, and I was curious about *Pain Creature*; therefore, I interacted with it by connecting all the components. On the second day, I was searching for comfort and relaxation, and I was also looking for some gentle actions to alleviate my boredom; accordingly, I engaged with *Warm Touch* and *Flow*. Finally, on the third day, I was driven by the sensation of a strong stretch and I could not curb my yearning during my morning yoga flow; hence, I started my interaction with *Flesh* and then added *Tectonic Plates* and *Burden*. In doing so, I corresponded with my body thoughtfully as a caring act. In addition, each of my engagements with *Pain Creature* revealed some of

the affordances of each component of the soma extension, specifically regarding their sensory kinesthetic qualities.

“A situation that moment by moment opens up a certain world and certain kinetic ways of being in that world [---] a certain way of moving calls forth a certain kinetic world and a certain kinetic world calls forth a certain way of moving” (Sheets-Johnstone, 2011, p. 424). *Flesh* opened the world of deep stretch through which I felt my corporeal existence vibrantly; the materiality of my body became apparent in my perception; therefore, I felt the juiciness and fleshiness of myself through a strong feeling of the interdependency of body parts. It facilitated movements that accentuate connectedness, heightening the senses of interoceptive touch and proprioception that play a significant role in perceiving the relationship between body parts and their spatial organisation (Figure 31B). *Burden* existed in the world of agony; it stimulated the challenging situations that emerged in the experience of pain and augmented the feeling of restriction. It reminded me that chronic pain is a permanent part of the body that may constrain kinesthetic abilities. Although one can find new possibilities for movement in mindful engagement with the body, through my interaction with *Burden*, I practiced the restricted sense of pulling that made a space for the pain and for me to stay and be together (Figure 31A). *Burden* and *Flesh* felt heavy and strong in terms of tactility that echoed my soma, whereas *Tectonic Plates* felt lighter to the touch, it felt burdensome like some bulky lump that I could not know where to place inside my body. It facilitated the exploration of angular movements where my body acted like a layer of earth where each layer tried to find its place in the body (Figure 31C).

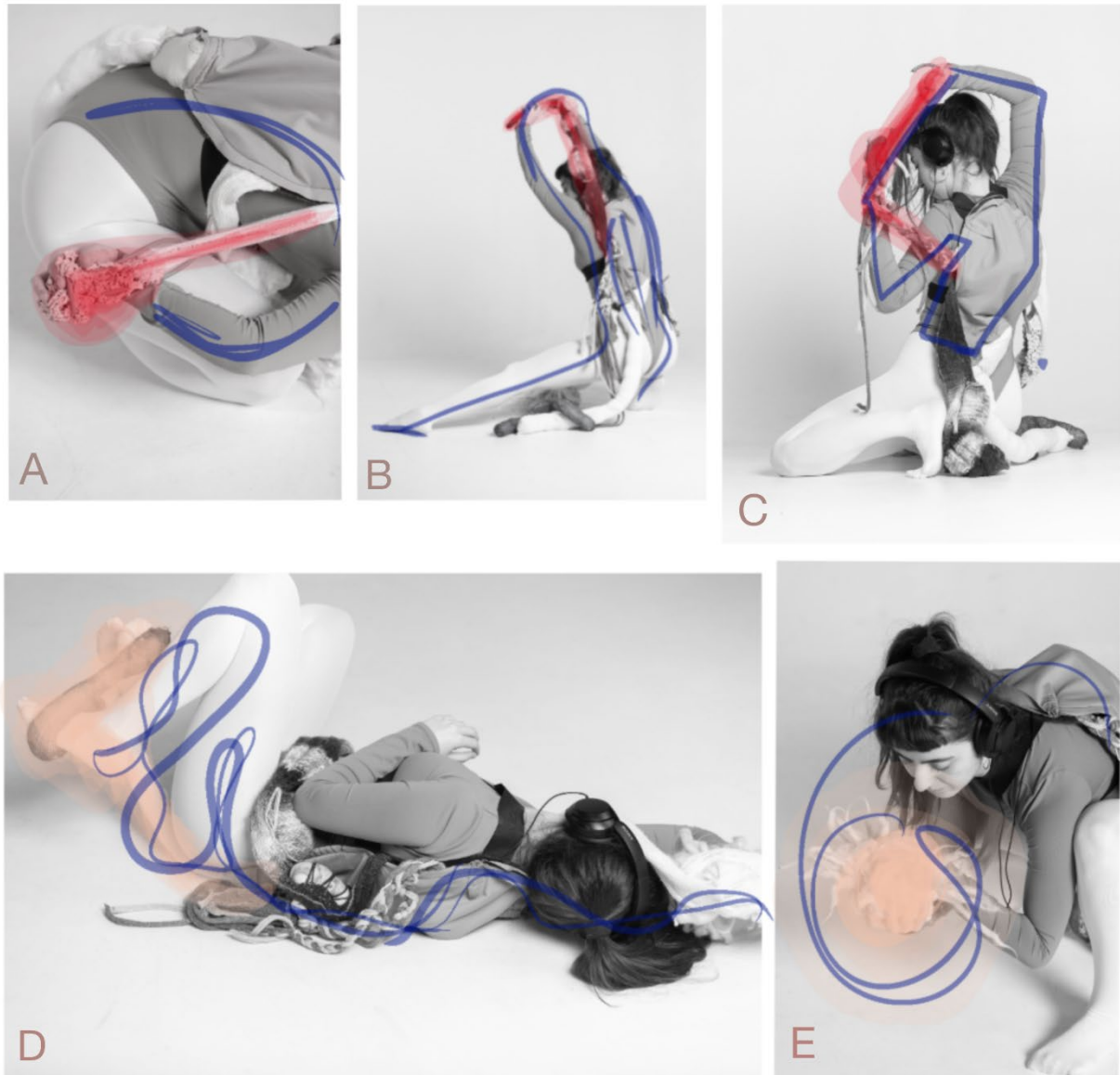


Figure 31. The visuals reflect what kinds of kinesthetic interactions are afforded by each pain component of *Pain Creature*. Photographs by Kadri Tiganik. Illustration by Arife Dila Demir

Through *Warm Touch*, I experienced a soft and gentle bodily engagement that promoted the feeling of compassion toward my own body. The movements that were expedited with it were driven by a strong sensation of touch and being in contact with the other, the other who is also part of the self. In moving through *Warm Touch*, I touched and moved with it while feeling being touched by it (Figure 31E). Finally, *Waves* resonated with a smooth disruption of the daily flow that is run by the clock; it became like a portal that took me to a slow-paced world where I was able to engage with gentle explorative bodily movements (Figure 31D). It was not only a disruption of the time that is driven by the clock, but it was also a pleasurable interruption of the agonising pain in which I felt the soft connection of my body parts unlike *Flesh* that provided a tenacious sensation of connection. These sensory kinesthetic affordances of all components revealed the connections between them, and then I drew Figure 32 to illustrate those

connections based on my living with *Pain Creature*. The relations drawn in Figure 22 are temporal, solely representing the relations that emerged from my three-day experience, yet those relations may change in different times and spaces, as well as in engagements with other individuals. According to my experience, *Burden* and *Tectonic Plates* entangled each other, connoting the living practice of being with the agonising sensations of pain. *Warm Touch* and *Waves* strongly signify the alleviated state of pain that does not necessarily imply the removal of pain but rather stands for making peace with the body in pain. So, they can ease and lighten the *Burden* of pain on the soma. In between these opposite yet still connected ends, *Flesh* was neither there nor here; it manifested a strong presence of pain that can be both tortuous and soothing.



Figure 32. The visual represents how each component of *Pain Creature* entangled with each other during my process of living with it. Illustration by Arife Dila Demir

As discussed above, *Pain Creature* afforded various sensory kinesthetic engagements that opened up new possibilities for movement and those of being and living with chronic pain, contributing to my somaesthetic journey. Living with *Pain Creature* also revealed some frictions; the challenge that arose in my use of *Pain Creature* was to find time or, more specifically, make time to settle into the bodily experiences of being and living. In the hectic flow of life, it became a challenge to make space for the self to correspond to the body. There is a vicious quandary in not being able to make this time because the pain sensation disrupts this quantitative time that is operated by the clock, heightening the awareness of passing time. Pain alters the time perception, and every passing second becomes dreadfully longer (Hovey et al., 2018). When I am fighting against my pain, trying to ignore it, I am always stuck in an agonising time where I become motionless like a corpse. However, healing entails acceptance and time for settling

into bodily experiences (Hovey et al., 2018). This time is to have a mindful dialogue with oneself to correspond with the pain. On one hand, *Pain Creature* aided me in having such time; on the other hand, it created a challenge to find the time.

In terms of testing, two frictions emerged: 1) conscious awareness of being watched by the camera, and 2) limited engagements with *Pain Creature*. I video-recorded my interaction with *Pain Creature* to capture the temporality of my experience as well as to have visual documentation to later use to elicit my felt experience in combination with my journal writings. When I decided to use the soma extension, first I had to set the camera where I plan to use it; and if I moved away from the camera, I had to change to its location. In using a camera, I did not feel restricted with my movements or worry about how I would look on the camera because I knew that only I was going to see the footage, and sharing the visuals with the public was up to me. During the test week, I thought about engaging with *Pain Creature* one more time but did not do so because I felt lazy about using the camera. The camera became an extension of *Pain Creature* that day. Finally, I only engaged with *Pain Creature* three times whereas a longer period of living with it may have revealed a deeper versatile inside regarding its affordances and frictions. Despite the limited use, my living with *Pain Creature* resonated with the temporality and changing dimensions of my pain experience, bringing forth the affordance of each component.

To sum up, the analysis of my living with *Pain Creature* illustrated how a soma extension that constitutes the versatile aspects of a chronic pain experience can echo the temporality of the pain experience. By affording different bodily interactions each component of *Pain Creature* corresponded with the needs of the body that initiated each use. Through this corresponding engagement, the soma extension enriched my somaesthetic becoming, providing new bodily perceptions in relation to my pain. New perceptions emerge when an interaction happens between material affordances and the agent, where new possibilities for action dynamically unfold through this interaction (Kronsted & Gallagher, 2021). In other words, every use of *Pain Creature* will create different possibilities for action for the wearer. Similar to the body in pain, notions of temporality and dynamic qualities are woven into the very fabric of *Pain Creature*.

5.4.2. Designing With/For/Through Pain

The creation of a soma extension to generate the somaesthetic awareness of chronic pain requires *designing with/for/through pain* as a methodological approach; through such an approach designers can gain substantial insight into the peculiarities of pain that can inform their designs. The *designing with/for/through pain* approach is primarily based on bringing about the qualities of the pain experience, specifically the discomforting and relieving aspects of it in the design artefacts. This approach unfolds in two phases: 1) *somatic exploration* which includes the cultivation and elicitation of the felt experience of pain, and 2) *material exploration* which is the phase of forming a physical artefact that is the embodiment of the pain experience. I offer three methods to be applied in both phases of this design methodology: 1) *moving through pain*, 2) *listening to pain*, and 3) *thinking with pain*. In designing *Pain Creature*, I did not apply these methods in tandem; rather, some were employed at the same time while some others were used in various orders during the different phases of the design process. In what follows, I will discuss the use of this methodology and its methods based on my design process.

Somatic exploration, the first phase of designing with/for/through pain, starts with the cultivation of the felt experience of pain which is the first step to understanding the phenomenon in question. It is through our moving bodies that we experience the world and ourselves (Merleau-Ponty, 2002); our cognition is based on this kinesthetic interaction through which we develop new perceptions (Shapiro, 2014; Sheets-Johnstone, 2011). Therefore, to acquire an understanding of pain, I suggest that the somatic exploration begins by *moving through* and *listening to the pain*. Pain wants to be heard and understood; hence, pain

attempts to communicate with the body through different means, amongst which the most prominent ones are tactile and auditory signs. Tactile signs indicate the location, textures, and patterns of pain; that is, wavy pain, stinging pain, pointy pain, etc. Similarly, auditory cues provide the sound qualities of those pain locations, textures and patterns. In this phase, the movements are initiated by those tactile and auditory signs that constitute the material and sensory qualities of the pain experience.

The cultivation part of the somatic exploration should be documented; therefore, the designer can later articulate those documented felt experiences in the elicitation part through *thinking with pain*. To acquire otherwise unnoticed dimensions of the felt experiences involves combining visual and textual elicitation tools (Demir, Kuusk, et al., 2022); hence, textual and visual documentation is needed for use in such an elicitation stage. I suggest using video recording to capture the temporal unfolding of the moving body and using keywords for the textual documentation of the felt qualities of the pain experience. Here the keywords are employed to provide insight into the sensory and material qualities of pain that inform the creation of the artefact. The cultivation process can last as long as the study requires, and upon the completion of this process, *thinking with pain* begins to elicit the cultivated experiences that will aid the process of creating the artefact. The aim of *thinking with pain* is to generate a conceptual understanding of the different qualities of a chronic pain experience that may inform the material and interaction qualities of the designed artefacts. Accordingly, the visual and textual documentation should be analysed to form those different concepts and qualities of pain. To do this, I first propose re-watching the videos to extract images that resonate with the documented keywords. In doing so, the designer will have a collection of visuals that represent keywords and by looking into these visual representations, the designer can combine and group the keywords that address similar qualities of the experience. After combining similar keywords, the designer would acquire the different dimensions of a chronic pain experience to inform the design and can transition into the material exploration stage.

The material exploration phase is the creation of an interactive artefact as the embodiment of the pain experience; it starts with *thinking with pain* to aid the designer to ideate on possible materials, making techniques and interaction modalities for the intended design artefact by looking into the generated pain concepts during the somatic exploration phase. Later, the designer can start exploring different materials and techniques to create samples by choosing suitable options. During the material engagement, the designer will be working with tangible and intangible materials, such as sound. The decisions about material, form and shape are also informed by the intended design modalities. During this explorative phase, the designer needs to *move through* and *listen to* the materials in order to gain a bodily understanding of the effects of various materials on the soma and be able to determine specific materials that reflect the aspects of pain to be applied to the making of the artefact.

To sum up, designing with/for/through pain is a design methodology that can be applied to a design research process that aims to cultivate somaesthetic awareness in relation to pain. This approach entails careful and thorough engagement with pain to acquire detailed accounts of the chronic pain experience. Designing with/for/through pain proposes a different approach to pain that does not consider the direct alleviation or removal of agonising pain; it searches for alternative ways of communicating with pain to become anew with it.

5.4.3. Strategies for Designing Engaging Soma Extensions

The second case study resulted in four design strategies for increasing the bodily engagement of soma extensions. Cultivated through the experience of five people with chronic pain, who used the *Caring Companion* kit (see Chapter 4), these strategies are conceptual design actions that consist of care, companionship, somatic engagements, correspondence, time, and non-habitual bodily interactions. I

applied these strategies in designing *Pain Creature* (see Section 5.3); during the analysis of the affordances and frictions of *Pain Creature*, two new strategies emerged: 1) *designing for temporality*, and 2) *opening a space for Kairos in daily life*. I combined a previously proposed strategy of *supporting somatic engagements in daily life* with the newly revealed second strategy as it comprises the old one. Accordingly, the revised strategies consist of five design actions: 1) *building a companionship*, 2) *unveiling the discomfort*, 3) *creating room for improvisation*, 4) *designing for the temporality*, and 5) *opening a space for Kairos (qualitative time) in daily flow* (Table 6). In what follows, I will present those two newly formalised strategies.

Table 6. Five design strategies – three revealed in the second case study and two in the third case study – for designing engaging soma extensions (movement-based interactive textile wearables)

Building a Companionship	Unveiling the Discomfort	Creating a Room for Improvisation	Designing for Temporality	Opening a Space for Kairos in the Daily Flow
Inducing feeling of togetherness through interactive artefacts to support people's journeys with pain.	Explicating the versatile qualities of pain through interactive artefacts providing non-habitual communications with discomforting experiences.	Supporting improvisational bodily engagement rather than strictly choreographing the interaction between the bodies and the artefacts.	Reflecting the temporal qualities of pain in design and supporting the notion of temporality through the interaction modalities of the artefacts.	Providing a reflective space for bodily engagements to settle in and reflect upon the felt sensations.

The inquiry taken in designing *Pain Creature* was based on the articulation of the changing needs of the body in relation to pain that represents the temporality of bodily experiences. As everyday sensations of this experience change and reveal new dimensions, I discussed that even in the existence of chronic pain we can examine temporality. A study of circadian variations in the pain experienced by people with hand osteoarthritis illustrated fluctuations in pain intensity and stiffness caused by pain (Bellamy, 2002). As pain dynamically unfolds over time, an increase in pain intensity causes a rise in depression levels (Pagé et al., 2022; Schneider et al., 2012, 2018). Considering the daily changes in pain and its influence on the soma, design artefacts that wish to explicate pain must explore different appearances and aim to reflect various dimensions of pain as well as possible. When designing for temporality, designers cultivate an understanding of what kinds of emotions, sensations, and feelings are evoked by different dimensions of pain and develop their designs accordingly. For instance, in *Pain Creature*, five dimensions of pain represented temporal qualities; these qualities took different physical forms and became different components of the soma extension. And considering the daily changes of pain, these components were designed to be used all together, individually, or in desired combinations according to the pain experience of the wearer. In doing so, *Pain Creature* acted as a practice for building new ways of being, moving, and living with versatile aspects of pain for the wearer that was enabled by designing for temporality.

On the other hand, during the analysis of living with *Pain Creature*, the notion of lived time or *Kairos* appeared. In cultivating somaesthetics, one needs time to settle into bodily experiences to be in the moment and encounter embodied sensations. As *Kairos* welcomes any bodily sensations to be experienced, in living with chronic pain, it might be the time to suffer (Hovey et al., 2018). It constitutes a

myriad of possibilities and allows one to re-story the experience with chronic pain, hence supporting new becomings with pain. Respectively, I proposed *opening a space for Kairos in the daily flow* as the fifth design strategy, suggesting that the soma extensions must support diving deep into bodily experiences and creating a space for exploration and self-reflection in *Kairos* time. Finally, the second case study proposed a strategy called *supporting somatic engagements in daily life* that contemplated that the soma extensions must provide conceptual and practical insights grounded in somaesthetics. I regarded that this can be achieved in *Kairos* where one experiences the flux of their bodily sensations through the soma extensions. Therefore, I combined this previously offered strategy with *opening a space for Kairos in the daily flow*.

5.4.4. Inviting the Notion of Lived Time for the Expansion of Somaesthetic Understanding

But in health the genial pretence must be kept up and the effort renewed – to communicate, to civilize, to share, to cultivate desert, educate the native, to work by day together and by night to sport. In illness this make-believe ceases. Directly the bed is called for, or, sunk deep among pillows in one chair; we raise our feet even an inch above the ground on another; we cease to be soldiers in the army of the upright; we become deserters.

(Woolf, 2021, p. 32)

As Woolf writes, in the existence of illness everyday ‘reality’ shatters into pieces and a new way of life comes into play where one becomes a deserter in agony. This new life shatters the integrity of the body challenging the sufferer with the notion of the temporality of bodily health as well as the ephemerality of pain itself. The bodily perception of the sufferer is then altered by these momentary changes. In living with *Pain Creature*, I realised that pain appears in a ceaseless change and each of the many appearances of pain altered my perception and my kinesthetic unfolding in the everyday flow. This changing aspect of pain resonated with temporal aspects of bodily experiences that invited the notion of time and its role in our somaesthetic becomings. We cannot perceive ourselves independently from time; self-consciousness and time-consciousness are bounded. Brough (2001, p. 29) writes, “[a]ll of the tasks and objects and activities that form the stuff of our daily lives are soaked with time. Collectively, they form the realm of temporality; and our consciousness of them, whatever else it may be, time is consciousness. We are not only beings in time but beings whose very fabric, mental and physical, is temporal”. We cultivate our sense of self and the world in the passage of time by experiencing temporal phenomena that appear to us.

Those temporal objects appear to us in the living now (Toombs, 1990), and they can alter our perception of time. “[T]he now is an elastic form.... depending on what content ‘fills’ them [past, now and future] can expand or contract” (Brough, 2001, p. 38). The elasticity of time invites two concepts of time, objective time and subjective time, which can also be referred to respectively as *Chronos* and *Kairos* in Greek (Hovey et al., 2018). In the constant flux of time, temporal objects with different contents appear to us and we experience them in the living now; when the content of those appearances is discomforting, time perception dilates. It has been discussed that time ceases to flow in the experience of pain (Hovey et al., 2018; Nilsen & Elstad, 2009; Toombs, 1990); the unwelcomed appearance of pain contracts the past and future and expands the now (Brough, 2001).

“Our perception of time changes with pain, and our seconds, minutes, hours, days, months, and years are painfully longer, more pronounced, dreaded, and insufferable” (Hovey et al., 2018, p. 98). In the subjective experience of the sufferer, the smooth daily flow is disrupted. The objects that are available in our perception of the living now are perceived in relation to the past and future. The collection of past

memories of pain destroys the future plans that were anticipated before pain and now forced to be changed. Brough writes that what happened in the past remains in disparity with what is happening now that disrupts the smooth transition to the future. Unwelcome events entail involuntary changes; they “may signal the end of oneself and beginning of another, thus challenging the very sense of continuity that time consciousness constitutes” (Brough, 2001, p. 40). Therefore, they may suspend the plans that the self dreamed of before pain, and the forced changes create the expansion of the now where time stands still, providing an eternal time and space for the person who is suffering. This unwelcome experience of pain may create new future anticipations that are filled with agony and suffering where the experiencing self becomes a captivated object who forcefully lives through difficult experiences. Kay Toombs (1990, p. 228) writes about how the experience of the object in the living now influences future anticipations:

For example, when I hear a melody, I hear not only the present note which is now sounding but I hear it as succeeding the note just-past which I still retain in my present consciousness. Furthermore, in hearing the present note, I anticipate a future note which will follow it as the melody unfolds temporally.

Similarly, just-past appearances of pain are retained in the consciousness causing painful predictions for future experiences; this agonising anticipation of the future dynamically unfolds in the temporal flux of embodied experiences. Especially in the experience of chronic conditions, the presence of pain becomes a learnt experience and anticipating a painless future becomes a challenge. Yet, imagining otherwise is still possible; to imagine other ways of being and living one needs to come to terms with a new temporal being and accept her situation. Brough writes that the sense of continuity is what enables a person to revive from pain and capitulate to the conditions of the painful body. This surrender is not necessarily a passive where the person leaves herself to the mercy of agony. Rather, it is a conscious acknowledgement of pain where she communicates with it to develop new ways of living and being. According to Brough (2001), after the revelation of pain has been absorbed, the person can obtain less agitated understandings and practices of living through the momentary continuum of life.

In other words, once the person absorbs the shock of the declaration of pain, she can then cultivate an even better understanding of the temporal continuity of life that can drive her actions to become new with pain. Becoming a new with chronic pain is a search for other ways of living with it by acknowledging that the removal of it is not possible. Healing in the context of chronic pain “is ‘settling into’ and learning to accept rather than avoiding the pain” (Hovey et al., 2018, p. 98). Settling into the lived experiences and acceptance become the necessary first steps of the somaesthetic journey in chronic pain. It is only then that a person can attend conscious awareness of pain and understand it – the second level of somaesthetic awareness. Following that, corresponding with pain through cultivating self-caring practices is the third level of the somaesthetic journey. Hovey et al. (2018) discuss that as much as *Kairos* is the time to suffer, it also constitutes the possibility of creating new life stories, unlike *Chronos* time, which isolates the person from bodily experiences by reminding her of the passage of time and appointments to catch. *Kairos* is the moment to experience objects that appear to us now and to create new experiences.

Kairos invites conversation, through reflection in a hermeneutic space, with its own sensibility, where one loses their sense of isolation and suffering and returns to finding solitude and peacefulness, even with Chronos lurking in the background. Whereas Chronos demands a surrender through weakness, a breaking or wearing down over time, Kairos gently provokes a type [of] surrender that reveals our denial of the situation with a reality that the pain is with the body but the suffering belongs to the person. ...It creates a space where we do not expect a cure but rather provokes a

meditation about how my life might become better and still evolving. ...to learn that healing is not a cure, but rather a means to learn to live well with pain.

(Hovey et al., 2018, p. 99)

Through opening a space for reflective dialogical engagements with bodily experiences *Kairos* supports somaesthetic becomings. How a person can re-story her life of suffering into other ways of being with pain is based on the right time to arrive for that particular person. Considering the temporality of experiences, the beginning of re-storying life with pain is not founded on a straight line. It unfolds on many tangled lines where relapses are part of the journey. These reworkings on pain will deepen our engagement with and our understanding of pain. “As we live every moment consciously like one long dance, we engage with the pain creatively. Re-storying ourselves is no different than the *Kairos* of creation when one paints, writes or composes” (Hovey et al., 2018, p. 101). In designing movement-based interactive wearables, we as designers can mediate these creative engagements with pain for somaesthetic becomings.

5.4.5. Artefact as the Non-verbal Communication of Pain

“Physical pain does not simply resist language but actively destroys it”, writes Elaine Scarry (1985, p. 14). Conveying the felt experience of pain to others is difficult, if not impossible. Pain patients are challenged to communicate their pain in clinical settings and that in turn influences the evaluation of pain by the medical practitioner (Padfield, 2011). Due to the multimodal aspect of pain, it does not have common metrics; therefore, it is problematic to share a person’s pain experience and even if she finds the words to describe her pain, she may keep her words from the physician, fearing what her description might connote. On the other hand, a sufferer can gain recognition from the other’s witnessing of her pain, and the understanding of one’s pain is essential for clinicians to assess and formalise better treatment options (Padfield & Zakrzewska, 2017).

Some of the traditional tools used in clinical settings for pain communication are images of facial expressions and standardised numbers (Fyhn & Buur, 2020). However common, these tools are not enough to transfer the lived aspects of the pain experience. In this regard, non-verbal creative tools can be used to support the communication of pain, providing a sufferer rich means to articulate her pain. Creative methods are considered as aids for pain dialogues when verbal expressions fail; for instance, exhibiting creative works that reflect pain can evoke various emotions for the audience helping them to develop insights regarding the pain experiences of others (Padfield & Zakrzewska, 2017). Metaphors allow people to express the unspeakable, and through metaphors creative works reflect lived experiences, emotions, feelings etc. The power of art, for example, stems from the metaphoric embodiment of expression (Padfield & Zakrzewska, 2017) and it can be used to communicate the pain of others. In this regard, photographs are explored as an alternative visual language to convey the meanings of pain. Artist and researcher, Deborah Padfield (2011) collaborated with pain patients and clinicians to create a collection of photos inspired by the pain expressions used by patients to be used as a supportive tool in pain dialogues in clinical settings.

Inspired by Padfield’s work, visual pain cards have been explored in patient-clinician communications (Padfield & Zakrzewska, 2017). Through the use of pain visuals, emotional aspects of living with pain become apparent for the clinicians that supported the communication between the patient and the doctor (Padfield & Zakrzewska, 2017). These studies illustrate that visual and textual language are complementary tools in pain communication. On the other hand, Padfield (2011) discusses the dangers of textual expressions in pain communication as words may have different connotations for others, depending on their subjective experiences, gender, religion, historical, or ideological background. I argue

that the same danger applies to visual expressions too, as they can generate various meanings evoking different emotions and feelings for individuals. In addition, the meaning of a word or a visual might also change for the sufferer, as temporal qualities of pain unfold in her embodiment. I believe that the use of various mediums of expression can support a sufferer to communicate temporal lived experiences of pain, allowing for better articulations.

In addition to the studies of alternative pain communication tools in clinical settings, in the design field, Christina Fyhn and Jacob Buur develop tangible pain scales in collaboration with six chronic pain patients as an alternative to traditional pain scales. They first developed eight different types of pain experiences that resulted in material metaphors. Following this, they created three personalised pain communicators for three patients (Fyhn & Buur, 2020). Similarly, this dissertation was my attempt to convey my pain experience to others through tangible, visual, auditory material metaphors. Throughout the three case studies, I explored ways of cultivating and explicating chronic pain experiences in the form of soma extensions. As a result, in the third case study, I designed *Pain Creature* by building upon what I had learned from the previous case studies. *Pain Creature* communicates pain via visual, tactile, and auditory means. The pain experience is subjective; yet, it has common temporal qualities that may resonate with various people who suffer from chronic pain. Accordingly, *Pain Creature* does not solely express my pain but others' pain experiences as well.

In doing so, it contributed to the non-verbal communication of pain through offering three forms of expressing sensory pain, specifically, visual, tactile, and auditory forms of expression. Each component of the soma extension conveyed different qualities of pain through these three sensory mediums. As presented in the design process section, these components were *Warm Touch*, *Waves*, *Heavy*, *Burden* and *Tectonic Plates*. They all had distinctive visual, sound and tactile qualities and can be used to articulate versatile aspects of pain. In addition, as a whole artefact *Pain Creature* was a multi-sensory representation of pain consisting of its different metaphors. It was not finalised but open to expansion and the addition of new pain components that will contribute to the multi-sensory communications of pain.

5.5. Summary

Through the third case study, I explored how *soma extensions might be designed to address the changing needs of bodies in chronic pain*. The inquiry of this final case study was informed by the insights gained in the first and second case studies. Building upon these insights, the final case study tackled the main research question: *How may movement-based interactive textile wearables as soma extensions facilitate the somaesthetic awareness of musculoskeletal chronic pain through mediating explicated interactions of it?* *Pain Creature* formalised the ways of cultivating and transferring the versatile dimensions of the chronic pain experience and illustrated how this can support somaesthetic becomings. In this case study, I conducted first-person research to cultivate temporal dimensions of pain. In doing so, I kinesthetically unfolded with my pain and carefully documented different aspects of this, and specifically indicated five pain dimensions *Burden*, *Flesh*, *Tectonic Plates*, *Warm Touch*, and *Waves*. These dimensions were manifested as different components of the soma extension, *Pain Creature*, mediating auditory-tactile-kinesthetic interactions to facilitate the somaesthetics of pain. The analysis of living with and designing the soma extensions helped me to understand the affordances and frictions of *Pain Creature*. In addition, the analysis revealed: 1) methodological implications for designing with/through/for pain, 2) the theoretical expansion of somaesthetics through inviting the notion of *Kairos*, and 3) presented the soma extension as the non-verbal communication of pain.

CHAPTER 6



Illustration by Arife Dila Demir

6. RESEARCH CONTRIBUTIONS: A NEW RESEARCH PROGRAMME - *DESIGNING WITH DISCOMFORT*

In this dissertation, I explored the research question: *How may movement-based interactive textile wearables as soma extensions be designed to facilitate somaesthetic awareness of musculoskeletal chronic pain through mediating explicated interactions with it?* I conducted three creative case studies, each examining different sub-questions in order to address the main one. The case studies: 1) revealed methods for designing close-to-body interactive artefacts that may facilitate the somaesthetics of pain, 2) offered generative design strategies to be applied in the process of designing such artefacts, and 3) extended the philosophical understanding of the somaesthetic awareness of pain. They suggested that movement-based multi-sensory interactive wearable textiles that explicate the versatile qualities of pain through tactile, visual and auditory materials can promote somaesthetic awareness for people with chronic pain. The case studies focused on the somaesthetics of chronic pain that is a type of bodily discomfort. However, driven by chronic pain, the methodological, design, and theoretical insights generated by this dissertation are situated in the somaesthetics of bodily discomfort in the larger perspective. Accordingly, these insights illustrated an approach for designing with/for/through discomfort revealing theoretical and methodological structures. In other words, they suggested a direction of building a design research programme building upon Redström's perspective on making a design theory that focuses on somaesthetic awareness of bodily discomforts. I call this programme *designing with discomfort*.

Redström (2017, p. 4) discusses theory as one of the possible makings of design; he considers theory not as something constant but rather something in an ongoing flux of extension, alteration and not only something to be articulated but also performed. Further, he writes that “theories have a direction, an orientation, a purpose”; therefore, we always have theories about something. In that regard, *designing with discomfort* is about a theory of the somaesthetics of bodily discomfort. He further elaborates on how we make definitions through design; “consider how a chair defines the act of sitting and how, therefore, designing a chair in a certain sense is a matter of designing what sitting is” (p. 31). Accordingly, when we design bodily interactions in the context of discomfort, we are designing certain kinesthetic repertoires, ways of engaging and being with the bodily discomforts in question. Redström defines two components of design research programmes: 1) the programme, and 2) experiments. Programmes are the basic beliefs, design ideals and intentions that form the basis, and experiments exemplify what design is according to the basis of the programmatic design research. He further writes that design programmes create transitionary worldviews and call for action based on these worldviews. “Thus, from the inside, the design programme is a call for action: ‘This is what designing is!’ From the outside, the design programme allows us to ask questions: ‘Designing could be this; what would be its implications?’” (Redström, 2017, p. 97). Through design programmes we can formulate provisional worldviews and explore what kinds of designs they may support. Therefore, the three case studies conducted in this dissertation are experiments in designing with discomfort exemplifying what being designed in this programme is based on its worldview.

Designing with discomfort is built on the idea that people living with bodily discomforts need more-than-symptom-relieving approaches to live a better life with their diseased bodies. As an alternative, it suggests the alleviation of diseased bodies starts with the acceptance of the situation and finding new ways of living and being with the discomfort. *Designing with discomfort* defines this process as the cultivation of somaesthetic awareness and discusses that kinesthetic engagements with externalised manifestations of bodily discomforts may facilitate such a process. In that regard, it calls for action to explicate qualities of discomforts through close-to-body wearable interactions that support multi-sensory kinesthetic

experiences. It proposes designing as an embodied process of investigating the diverse aspects of bodily discomfort in question and to materialise this via design artefacts. In other words, *designing with discomfort* proposes designing with/for/through bodily discomforts to promote somaesthetic awareness.

Designing with discomfort is my attempt to imagine alternatives of being, living, and designing for chronically diseased bodies focusing on externalising disturbing experiences rather than removing, alleviating, or suppressing them. It is based on the cultivation of felt experiences in relation to discomforting experiences and use this as a design source. By offering *designing with discomfort*, I aim to open a design space for diseased, disturbed, agonised bodies calling designers to challenge the normative approaches to bodily discomforts. The proposed programme is a design theory that illuminates the designing of close-to-body interactions with/for/through bodily discomforts and shaped by making, reading, moving, dancing walking, and thinking with/for/through discomfort. In proposing this programme, I contribute to design research, specifically, to the intersecting fields of HCI and interactive textiles. Within HCI, *designing with discomfort* is situated in embodied design approaches. It specifically takes inspiration from soma design theory that focuses on the cultivation of first-person somatic sensibilities for design use (Höök, 2018). Through building upon and moving beyond soma design ideals it focuses on the cultivation of the aesthetic sensibilities of bodily discomforts to support people who live with chronic discomforting experiences. Based on Barad's (2014) notion of diffraction, *designing with discomfort* adopts an iterative design process where we entangle the differences in felt experiences in the making of the artefacts. On the other hand, designing as a process of diffraction suggests a dynamic and iterative approach to designing to turning the research outcomes over and over again in the formation of new temporalities.

As discussed in the *Introduction*, in the section titled *Research Background and Related Works*, soma design projects have been focusing on pleasurable and comfortable experiences; only a few projects have tackled discomfort, and they do not consider discomfort as a chronic bodily condition. Soma design has brought an alternative way of designing, as opposed to the rapid design process; it suggested adopting a slow and thoughtful design processes and actively involving movement and felt experiences in design processes. Building upon that, *designing with discomfort* tackles the challenges that are brought forth by chronic conditions, such as how diseased bodies interact with the world and themselves, how they struggle with discomfort, and in what ways they need support. Accordingly, it presents a design repertoire for designing with/for/through discomfort. In addition, this programme contributes to the interactive design field by: 1) exemplifying alternative ways of designing for pain and discomfort where the field is mainly dominated by the pain-alleviation approach (see *Introduction*, section titled *Problem, Aims and Research Questions*), and 2) providing a design structure to materialise implicit bodily discomforting experiences.

To sum up, this dissertation contributes a design programme called *designing with discomfort*. The research programme unfolds the dissertation's theoretical and methodological contributions as the research programme extends not only the philosophy of somaesthetics but also design research methods to cultivate and articulate discomfort for design use. The research programme has emerged as a result of the three case studies that experiment via *designing with discomfort*. In what follows, I will present how the case studies came together as building blocks of *designing with discomfort*.

6.1. Extended Philosophy of Somaesthetics – A Theoretical Contribution

Designing with discomfort is primarily based on the idea of humans becoming in the constant flux of movement; we engage with ourselves and environments continually to cultivate meanings in relation to

what we engage with as we kinesthetically unfold. Bodies are the locus of perception (Merleau-Ponty, 2002) where humans as animated beings make sense of the world and themselves through movement (Sheets-Johnstone, 2012); therefore, cognition is tightly linked to sensorimotor capabilities (Shapiro, 2014; Wilson, 2002). Accordingly, *designing with discomfort* is based on phenomenology (Merleau-Ponty, 2002; Sheets-Johnstone, 2011) as well as embodied cognition (Shapiro, 2014; Wilson, 2002) and considers embodiment and situatedness as an essential part of meaning-making processes. Additionally, the somaesthetics of Shusterman is another theory that contributes to the formalisation of the worldview of *designing with discomfort*. Somaesthetics simply suggest that humans can improve their living practices through cultivating somatic awareness and aesthetic appreciation skills (Shusterman, 1999, 2006). I discuss the role of these three theoretical backgrounds in this dissertation in depth in Chapter 2, and in this section, my aim is not to reintroduce these theories, rather I aim to illustrate how the extension of somaesthetics that emerged throughout the case studies builds the philosophical foundation of *designing with discomfort*.

As discussed previously, the proposed design programme aims to facilitate the somaesthetic awareness of bodily discomfort, bringing the idea of cultivating sensory aesthetic understanding through the existence of agonising, disturbing as well as pleasant and relieving bodily experiences. Pleasure can be acquired from illness and pain, where pain and everyday illness can be informative, teaching us to perceive bodily sensations clearly (Shusterman, 2019). In answering to critics of the meliorative approach of somaesthetics, Shusterman (2019) discusses that by ‘feeling better’ he refers to enhancing our experience of living that does not merely regard improving bodily appearance and performance. By giving space to pain – discomfort, illness, disability, stress – he writes that in learning to be perceptive to such sensations bodies can find ways to improve their lives through responding to them (Shusterman, 2019). On the other hand, bodily discomforts as general physical irritations are also explored in the context of somaesthetics (Tschaepé, 2021). Tschaepé considers the somaesthetics of discomfort as a skill that helps us recognise experiences that cause discomfort; that is, enhanced bodily awareness. He discusses through such heightened awareness that we can communicate our discomfort better with others and emphatically understand others in discomfort.

Yet, neither Shusterman nor Tschaepé touch upon the somaesthetics of discomfort in depth, leaving the cultivation of such awareness in chronic conditions uncovered. Through *designing with discomfort*, I open up a space for exploring the sensory aesthetic cultivation of bodily discomforting events that are chronic conditions disrupting the flow of bodies. *Designing with discomfort* interprets the ‘feeling better’ and ‘being better’ notions of somaesthetics as becoming new, and defines the somaesthetics of discomfort as cultivating sensory awareness and appreciation skills to become new with the bodily sensation between and beyond the discomforting and the pleasant. The worldview of *designing with discomfort* is based on the idea of relieving chronic conditions, not through the removal of the conditions but rather finding new ways of living and being with them and adopting a somaesthetically driven life to respond to changes that might emerge in our bodily experiences. It proposes acceptance as a prerequisite for the somaesthetics of discomfort journey. To become anew with our bodies in constant change we need to recognise those changes rather than suppress them. Accordingly, design artefacts using *designing with discomfort* aim to explicate disturbing experiences for diseased bodies to communicate and transform with the discomfort. *Designing with discomfort* perceives the somaesthetic journey as a multi-layered somatic exploration, where the explorer continually moves in between. Below I will present the multi-levelled understanding of the somaesthetics of discomfort and then discuss how it relates to the perception of time as part of the search for a place for somaesthetics in our everyday flow.

The multi-levelled understanding of the somaesthetics of discomfort emerged in the second case study (see Chapter 4, Section 4.4); while analysing the participant narratives, I came to realise that bodily awareness is changing between different levels. Three levels are defined as a result that concern diagnosing, understanding, and corresponding with discomfort to cultivate self-caring practices. These layers support each other; that is, the second cannot be achieved without the first and third layer cannot be achieved without the previous ones. This does not mean that when a person attains the third level she will remain there; somaesthetics is a temporal journey and it is a constant negotiation with our changing bodies. As our bodies change and bring forth new challenges and discomforts for us, we may experience setbacks in our journey of becoming new. On the other hand, as I illustrated in my autoethnographic interludes throughout the case study chapters, my own transformation with my back pain was much easier than my challenging journey with IBS, which I struggled to accept. Hence, we may find it easier to find new ways of living with certain kinds of bodily discomfort, while also struggling to even start the journey of becoming with others.

The first level considers being aware of bodily sensations and different qualities of discomfort. This is similar to what Shusterman and Tschaepé discuss as developing a bodily sensibility to recognise the discomforting experiences. The second level focuses on articulating the meanings of the recognised disturbances and what they entail; in other words, moving beyond acknowledging the discomfort to developing an in-depth insight into it. And third level is about corresponding with what is articulated in the second level that leads to the cultivation of self-caring practices in relation to the discomforting experiences. Through these levels, *designing with discomfort* draws the transient journey of the somaesthetics of discomfort and suggests not to perceive these layers as static and incremental but rather dynamic and entangled. It suggests that in designing with/for/through discomfort, designers must consider how to support this dynamic journey for people with diseased bodies. It invites designers to engage with these three levels thoroughly to design bodily interactions to support deeper somaesthetic unfoldings of discomfort.

Starting from acceptance, neither part of the somaesthetic journey could happen without attentive consciousness and reflection. As discussed in the Theoretical Background (see Chapter 2), we first experience phenomena at the pre-reflective level and we make sense of these through reflection; this is when they become cogito. Similarly, we experience discomfort somatically first at the pre-reflective level. Through guiding our conscious attention to it we can recognise our discomfort, how it influences us, what kinds of situations trigger or relieve it, what kinds of care is needed and what kinds of new ways of living are possible with this certain kind of discomfort etc. Such somaesthetic expeditions call for time and space for the diseased bodies to settle into their bodily experiences to understand and reflect upon them. Discomforting experiences reveal themselves in the flow of everyday life, and depending on their felt qualities they may influence our perception of time (Brough, 2001; Toombs, 1990). For instance, in the experience of a pleasant phenomenon we may perceive that time goes fast whereas in the experience of pain minutes may become hours. In some cases, bodily experiences may often remain hidden in the flow of everyday life unless an acute phenomenon claims our conscious attention. Similarly, in the experience of bodily discomfort even though it is agonising as it becomes part of the bodily reality, we may not pay attention and suppress these discomforting sensations to ‘function’ in the daily flow.

In that regard, *designing with discomfort* intervenes in the daily flow through explicating the discomfort and making the diseased bodies unable to neglect bodily sensations but encounter them. In doing so, the artefacts of this design programme call for immediate attention to the body claiming subjective time, *Kairos*, and space to become new with the discomfort. As opposed to *Kairos*, objective time, *Chronos*, is where we often neglect bodily experiences in the hectic passage of time for organised meetings, schedules

etc. *Designing with discomfort* aims to overcome the neglect of the body in *Chronos* and invites the notion of *Kairos* in somaesthetic thinking. In other words, it focuses on creating artefacts that may support the creation of *Kairos* in daily life for diseased bodies to communicate with their discomforts. In this dissertation the notion of subjective time emerged in my analysis of the third case study, where each use of *Pain Creature* was a pause in the daily flow to engage with the temporal appearances of my pain experience. As an example of discomfort design, *Pain Creature* illustrates how an interactive artefact can generate *Kairos* in daily life corresponding with the versatile qualities of a discomforting experience. To sum up, *designing with discomfort* provides a multi-layered understanding of the somaesthetics of discomfort where diseased bodies can engage with their bodily sensations continuously as the temporality of disturbing phenomena unfolds. It weaves the notion of *Kairos* into the somaesthetics of discomfort suggesting subjective time should be generated by designed artefacts to support dialogical conversation with bodies in discomfort.

6.2. Designing With/For/Through Discomfort – A Methodological Contribution

Designing with discomfort primarily seeks two qualities when designing with/for/through discomfort: 1) kinesthetic engagements, and 2) explicating versatile qualities of discomfort. Accordingly, this design methodology is based on an intimate engagement with diseased bodies in motion to cultivate and articulate the felt experiences of discomfort that can inspire movement-based bodily interactions. It is through our bodies that we make sense of the world and of ourselves (Merleau-Ponty, 2002; Sheets-Johnstone, 2011); respectively, in the design field non-habitual bodily engagements were discussed as a way to develop new bodily perceptions (Höök, 2018; Loke & Robertson, 2013; Wilde, 2011b). Similarly, *designing with discomfort* considers non-habitual engagements as interacting with explicated discomfort through movement-based artefacts mediating multi-sensory experiences. Hence, it aims to combine different sensory stimuli when designing kinesthetic interactions.

Similar to the soma design process, the designing with/for/through discomfort approach of the proposed design programme consists of two phases: *somatic exploration* and *material exploration*. The first phase refers to the cultivation and elicitation of felt experiences, while the second phase considers the materialisation of these experiences as design artefacts. Growing on the soma design process, through these two phases I structure three methods to be applied in both phases to deeply engage with the discomfort in question: 1) *moving through discomfort*, 2) *listening to discomfort*, and 3) *thinking with discomfort*. In doing so, I offer a design process that primarily focuses on ways of cultivating and eliciting the felt experiences of discomfort. In the somatic exploration phase, *moving through discomfort* entails close examination of the discomfort in question through somatic practices (i.e., dance, yoga, tai chi), or through the non-habitual engagement of mundane bodily activities like walking. Following the above listed three methods, the somatic exploration phase can be applied to cultivate first and second-person felt experiences that will reveal nuances of the discomforts. On the other hand, in the material exploration phase, *moving through discomfort* refers to interacting with materials (i.e., fabrics, yarns, silicone) as well as with digital materials like sound that may be used in the design artefacts. In doing so, designers will gain an embodied insight into potential materials for realising their designs (Tomico & Wilde, 2016b).

In addition, *listening to discomfort* is highly integrated with *moving through discomfort*. It requires heightened attention to the discomfort while moving through with it to capture what it tries to communicate. In doing so, designers can acquire the location, sound, and tactile qualities of the discomfort that they are exploring, or in the material exploration phase they can acquire those qualities in the materials they are experimenting with. While moving through and listening to the discomfort, designers should document their experiences, and later on through *thinking with discomfort*, they can

elicit those experiences. Accordingly, in the somatic exploration phase, *thinking with discomfort* indicates making the documented experiences graspable to inform the design process. Whereas in the material exploration phase, *thinking with discomfort* is the first step where through looking into the articulated felt experiences, designers ideate on the material and interaction qualities of the design artefacts. These three methods and the two phases referred to as somatic and material exploration phases emerged in the third case study (see Chapter 5, Section 5.4.). Yet, how those phases appeared and how *moving through*, *listening to* and *thinking with* pains unfolded can be traced back in first and second case studies. For instance, in designing first iteration of *Squeaky/Pain*, I *moved through* my pain practicing a yoga sequence while *listening to* it, and in *thinking with* my pain, I realised that the sound was an essential element in the experience of pain that became the interaction modality to mediate kinesthetic interactions.

In *moving through*, *listening to* and *thinking with discomfort*, throughout the three case studies, I faced various frictions that I call designers to account for. *Moving through* pain aims at cultivating lived experiences of discomfort and lived experiences of using the *designing with discomfort* artefacts; therefore, it requires heightened attentiveness to the bodily experiences. In *Squeaky/Pain* the first iteration of the soma extensions became a distraction for one of the participants as it was too tight for him. Accordingly, in the making process designers can explore ways of designing adjustable artefacts that can fit different bodies or design for different individual bodies. On the other hand, in *Squeaky/Pain* when *listening to* my discomfort in the first phase of the design process, I solely focused on the agonising aspects, and I came to realise the relieving qualities of pain after the participant study (see Chapter 3, Section 3.2.). Then in *Pain Creature*, knowing that pain has multiple qualities, I was able to cultivate versatile aspects of my discomfort and translate them into the design. Hence, I suggest designers account for the multiplicities of our lived experiences and seek to harvest different meanings of the discomfort that they are studying. Lastly, in the material phase when *thinking with discomfort*, designers need to account for the features of the digital (i.e., sensors, actuators), and tactile materials (i.e., textiles). The materials have their own affordances and *thinking with discomfort* is a negotiation between the designer, the materials, and cultivated felt experiences. For instance, in *Pain Creature* the initial design idea was to represent six aspects of pain, yet the capacities of the digital materials led me to re-think the conceptual design decisions (see Chapter 5, section 5.4.).

As mentioned above, during the somatic exploration phase, lived experiences should be documented for design use. The first case study (see Chapter 3) presented various tools for eliciting first and second-person felt experiences of discomfort, which were later applied to the second and third case studies to articulate my and research participants' lived experiences. In addition, during the second case study, I applied narrative inquiry to reveal in depth their becomings with the soma extension. Therefore, in Table 7, I combined the elicitation tools that emerged in the first case study and the narrative inquiry as an elicitation tool illustrating how to apply each tool. When cultivating lived experiences of discomfort, designers must choose the relevant tools according to their studies and make iterations of these tools if necessary or implement new ones. *Designing with discomfort* discusses the difficulty of communicating discomfort especially through textual tools. Various thinkers and researchers in the context of patient-doctor communication have discussed the challenges of textual expressions of pain (Hovey et al., 2018; Padfield, 2011; Scarry, 1985). As an alternative to better convey the felt aspects of discomforting experiences, photographs (Harper, 2002; Padfield & Zakrzewska, 2017), creative works (Padfield, 2011), and tailor-made tangible pain scales (Fyhn & Buur, 2020) were proposed. The common ground for these explorations are concerned with discomforting experiences being complex and multi-modal; we should not rely only on one way of communicating such experiences but rather combine multiple modes of expression. Visual and textual elicitation tools were suggested as complementary methods to articulate nuances of bodily experiences (Demir et al., 2022, 2023). Accordingly, *designing with discomfort*

suggests that designers engage with different elicitation tools to capture otherwise hidden dimensions of discomfort.

Table 7. Methods applied for eliciting felt experiences of first and second-person perspectives and transfer the felt qualities of pain into designed artefacts

Method	Aim
Journal	A journal can capture the textual reflections of discomforts. It can be used to write long entries (see case study 1 & 2) or keywords that echo with the felt bodily sensations (see case study 3).
Video	Video recording can capture the temporal felt dimension of somatic exploration phases, enabling designers to catch otherwise unnoticed aspects of somatic engagements via observation of the self and others in motion.
On-photo body map	Photos can be extracted from the video recordings. On-photo body maps highlight the locality of the felt experiences and can reflect the lived qualities of discomfort in different movements.
Actual-size body map	Actual-size body maps capture the specific discomforting areas on the body and can inspire the visual qualities of the artefact. For instance, the shapes of the artefact can be manifested according to the figures that emerge on Actual-size body maps.
Traditional body map	The traditional type of body map is handy when working with other people where the creation of on-photo body maps is not possible. They can contain the unspeakable aspects of the discomfort.
Semi-structured in-depth interview	Interviews can help designers grasp participant experiences by guiding them to articulate their experiences.
Self-Interview	Self-interviews are a form of verbal self-reporting for designers to document their experiences. When the somatic exploration unfolds over one day, rather than using journal entries, for instance, designers may record their lived experiences through this tool.
Narrative inquiry	Narrative inquiry enables a detailed exploration of people's experiences; therefore, it can help designers to exemplify the individuals peculiar unfoldings considering their lived experiences of discomfort and the close-to-body artefacts (see case study 2).

I presented these tools to explicate the nuances of the felt experiences to be transferred to the design of close-to-body artefacts. When making artefacts, designers need to aim to create engaging bodily interactions that will support the conscious attention of the people on their bodily experiences. Therefore, they should create the sensation of a connection with the body rather than becoming alien to the body. The second case study (see Chapter 4) explored how soma extensions promote better somatic engagements and proposed four design strategies. These strategies were later reformed in the third case study and finalised as five actionable design strategies for designing engaging close-to-body artefacts (see Table 6 in Chapter 6). These strategies are: 1) *building a companionship*, 2) *unveiling the discomfort*, 3) *creating room for improvisation*, 4) *designing for the temporality* and 5) *opening a space for Kairos in daily life*. The very first strategy specifically focuses on building a companionship both as a seamless and synchronised interactive bodily extension and as an embodied ally. The second strategy focuses on explicating versatile dimensions of the discomfort not agonising yet disturbing enough to mediate non-habitual engagements. The third strategy suggests rather than choreographing entire bodily interactions, leaving room for people to creatively unfold through their bodies in motion to learn new ways of being,

living, and moving with their discomfort. The fourth strategy focuses on the temporality of bodily discomforts and proposes to design temporal interactions that can resonate with the changing aspects and needs of the discomfort in question. The fifth strategy highlights the need for *designing with discomfort* artefacts to provide space for *Kairos* time in daily life to facilitate somaesthetic engagements.

6.3. *Designing with Discomfort* as a Design Research Program

Designing with discomfort focuses on designing close-to-body interactive artefacts that act as a second skin and an extended part of diseased bodies. In other words, the *designing with discomfort* artefacts are extended body parts that explicate the discomfort through multi-sensory stimuli. These artefacts do not solely consist of tangible materials, such as fabrics, yarns, silicone etc. but they include digital materials such as actuators, sensors and microcontrollers that provide intangible material qualities (i.e., auditory and kinesthetics features). The making of these artefacts aims to explicate the discomfort through various sensory modalities and materials. This design programme aims to achieve kinesthetic interactions that can lead new bodily perceptions and accordingly, I suggest designers engage with the digital and tangible features of their designs to support such interactions. The three case studies illustrated that sound is a versatile modality for mimicking the discomfort as well as encouraging movement-based engagements. Hence, through this design programme, I invite designers to explore the potential of auditory stimuli.

As *designing with discomfort* aims at making tangible close-to-body applications, tactile materials also play an essential role. Throughout this dissertation I employed various textiles, fibres and making techniques to investigate different ways of representing pain through materials. As exemplified in *Pain Creature*, I suggest designers make use of different materials when reflecting the multiple aspects of discomfort. In addition, I propose approaching digital and tangible material ideation as a complementary process rather than working on them separately. In this dissertation, I chose to mediate discomfort through the sound and visual design of the soma extension. If designers wish to explore discomfort through tactile qualities, I call on them to carefully engage with this idea considering two notions: 1) using too many discomforting modalities can become overwhelming, and 2) physically agitating bodies that are already in agony. For instance, in *Squeaky/Pain* tactile discomfort was not yet the aim, the soma extension was too tight for P2 and that became an irritation and a distraction (see Chapter 3, Section 3.2.). Lastly, *designing with discomfort* addresses the diseased bodies; it neither aims to alleviate the discomfort nor remove the cause of the discomfort. It aims to explicate the discomfort of diseased bodies and to communicate with their discomfort through non-habitual engagements that cultivate somaesthetic awareness. Therefore, as designers we need to become attuned to the bodies we are designing for.

With the idea of attuning to the bodies we design for, *designing with discomfort* calls for ethical and caring practices as part of design research processes; accordingly, I invite notions of care ethics within design research (Howard & Irani, 2019) and the philosophy of the aesthetics of care (Saito, 2022). This is not merely so as to apply ethical institutional requirements for the participants in care research or the researcher in first-person research, but rather it is meant for the action beyond these institutional approaches. In addition, this call does not only consider ethics as an abstract concept, rather it accounts for materialising ethics through our design artefacts. As discussed above, *designing with discomfort* works with and for the diseased bodies that we need to care for in the design process, as well as through the end results of these processes, hence with the artefacts. Through the aesthetics of care, Yuriko Saito explores ethical and aesthetic sensibilities in care; she discusses that the aesthetics of care raises ethical concerns that consider materials as living phenomena that we can engage with through dialogical conversations. She writes that the ethics and aesthetics discourse has ignored the capabilities of objects to express care; the objects that we interact with can shape the quality of our lives formed by aesthetic and ethical decisions (Saito, 2022). Therefore, we need to also invite the notion of care as a material quality in

designing artefacts, and approach aesthetics, ethics and care as complementary notions when designing for diseased bodies.

In design research, ethics are discussed as modes of decision-making (Howard & Irani, 2019), not merely as lexical or intellectual principles but rather as a felt phenomenon (Garrett et al., 2023; Popova et al., 2022). Design ethics are situated (Howard & Irani, 2019) in constant negotiation; they should be co-created based on how the situations unfold with the people who are involved in the process (Lindberg et al., 2021). In other words, we need to maintain an attentive sensitivity towards ourselves, others, and our interactions with our participants, between the participants and artefacts, and ourselves and the artefacts. According to what these situations bring forth, we need to take ethically grounded caring actions. Howard and Irani (2019) define care as a practice of acknowledging the unfolding situations and taking actions accordingly. Garrett et al. offer a felt ethics approach to cultivate ethical sensitivity that can motivate ethical actions. They say these actions reflect our capacities to cultivate ethical insight which can be improved through somatic sensitisation (Garrett et al., 2023). Saito (2022, p.18) says that ethically caring practices and aesthetic experiences are similar in the way that they require “attentiveness, open-mindedness, receptivity, respect, collaborative spirit and activation of imagination”.

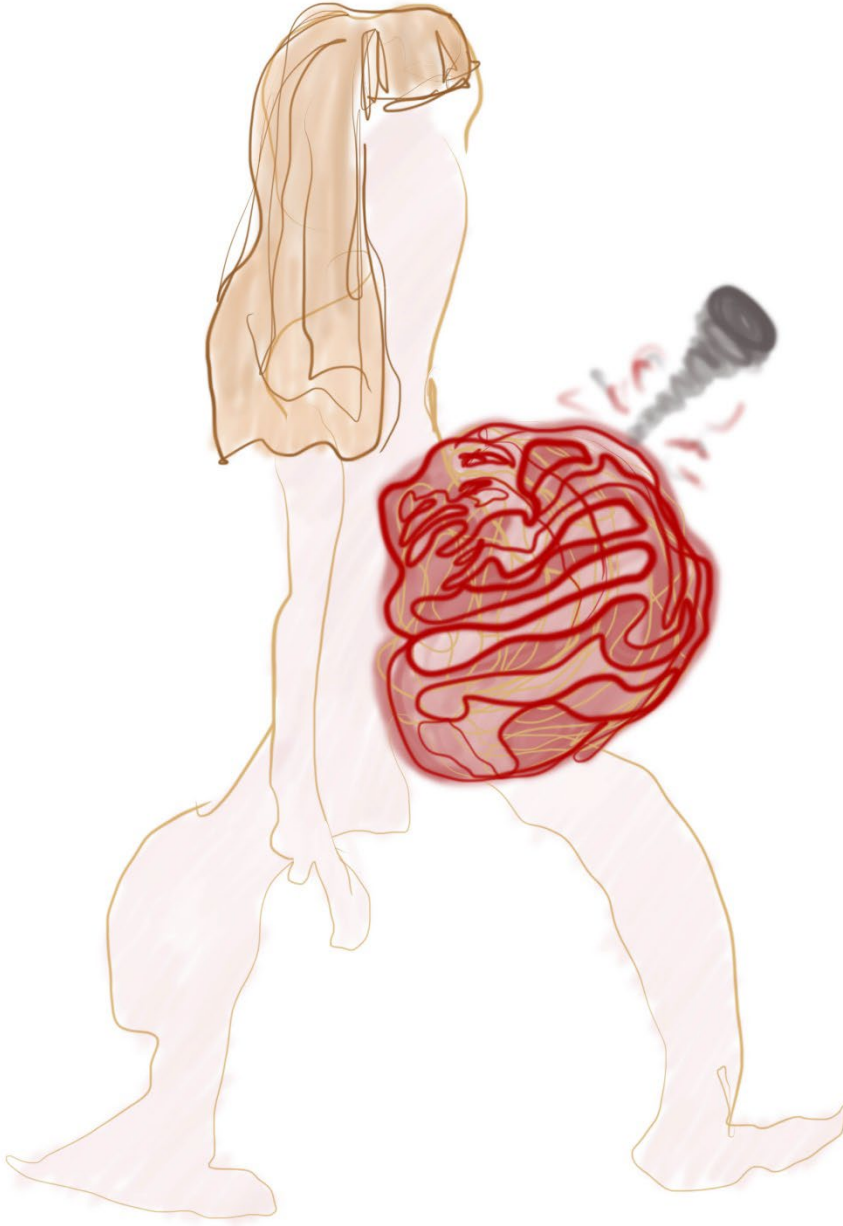
Through engaging with our somatic selves, we can develop ethical and caring sensibilities as we cultivate aesthetic appreciation skills. Based on this, through engaging with our bodies in discomfort we can develop insights into ethics, care, and the aesthetics of discomfort. Therefore, *designing with discomfort* suggests that designers start the design processes via first-person somatic explorations not solely to cultivate an in-depth understanding on the discomfort in question but to develop ethical and caring insights first towards themselves that can then also be extended towards others. Saito (2022) asserts that care ethics and aesthetics benefit from the first-person perspective in learning to relate to the other. When exploring the first-person lived experience of discomfort, designers become vulnerable, sharing and exposing their personal lives. Felt vulnerability can prompt reflection upon ethical decisions helping to develop ethical insights into one another (Popova et al., 2022). Through being vulnerable in engaging with their somatic discomforts, designers can resonate with their participants, acknowledging the emotional labour that they will be asking from them, and anticipating situations that may require careful attentiveness in participant studies. However, working with bodies is working with the unknown; designers cannot anticipate everything that may happen and this requires caring actions during the design process. For that very reason they need to maintain their heightened awareness towards themselves and their participants to respond to the situations that require immediate ethically grounded caring actions. Care ethics entails sensibility to oneself, others and situations, and tailoring actions accordingly rejecting universal rules (Saito, 2022).

To sum up, *designing with discomfort* proposes a design process consisting of two phases 1) *somatic* and *material exploration*, where designers can move through, listen to and think with discomfort to cultivate and articulate the lived aspects of the discomfort for design use. It offers elicitation tools to capture first and second-person lived experiences of discomfort that can be employed in the somatic exploration phase. It presents five design strategies to be applied to the creation of artefacts in the material exploration phase to design engaging close-to-body artefacts for the somaesthetics of discomfort. Finally, it discusses ethics and care as generative notions integrated into the design research process of *designing with discomfort* and suggests that they need to be cultivated and enacted continuously.

6.4. Designing with Discomfort Manifesto

- i. Bodily discomforts are *chronic somatic conditions* such as depression, fibromyalgia, irritable bowel syndrome, migraine, and chronic pain.
- ii. ***Design*** with/for/through *discomfort*.
- iii. Designing is *corresponding* with discomfort.
- iv. ***Move*** with, ***listen*** to, ***think*** with discomfort.
- v. Prioritise *kinesthetic interactions* as primary design modalities.
- vi. ***Explicate*** discomfort, do not suppress it.
- vii. Design for the *somaesthetics of discomfort*.
- viii. Acknowledge the *temporal nature* of bodily discomforts.
- ix. Adopt *more-than-symptom-relieving* approaches.
- x. Create *multi-sensory artefacts* that express the diverse qualities of bodily discomfort.
- xi. Artefacts are *physical manifestations* of bodily discomforts.
- xii. Cultivate *ethical, aesthetic, and caring sensibilities* throughout the design process.

CONCLUSION



12.05.2022

Illustration by Arife Dila Demir

This dissertation was an inquiry into the somaesthetics of bodily discomforts that were defined as chronic bodily events, such as migraine, fibromyalgia, depression, chronic pain, etc. The inquiry was based on the premise that through kinesthetically communicating with bodily discomforts we can cultivate new ways of living and being with them; that is, the somaesthetic awareness of discomfort. In addition, due to the different types of chronic pain that emerged at the beginning of this dissertation and during, I was interested in how we can communicate and engage with something that persists and does not leave the body by changing our habitual ways of living. I suggested deliberately engaging with our diseased selves and designing uncomfortable interactions that are informed and which explicate the bodily discomforts in question. I maintain that discomforting events constitute different qualities that range between agony and relief. In other words, such events are felt at various intensities and qualities that are not merely tormenting but also pleasing. Shusterman (2019) states that relief from pain might be stronger than the relief that emerges in pleasurable sensations. The relaxation that appears within a discomforting experience can have a freeing effect on the diseased body through being free from what is most disturbing. I considered pleasant and disturbing aspects not as opposing but as complementary qualities of discomforting experiences. Respectively, in this dissertation, I cultivated various qualities of chronic pain to prompt the design of interactive artefacts. I advocated that we need to communicate with the discomforting phenomena to understand and develop somaesthetic awareness of them; hence, in reflecting complementary qualities of discomforting experiences, the designed artefacts can afford such communications.

For interactive artefacts that explicate the discomfort, I specifically focused on interactive wearable textiles. As an interactive textile practitioner, I considered textiles as materials that are intimately close to the body almost like a second skin that can explicate the implicit disturbing phenomena outside, expanding the boundaries of the bodies. In this dissertation, I referred to those artefacts as soma extensions that mimic the various qualities of chronic pain, externalising this discomforting experience and mediating movement-based interactions. This dissertation deliberately sought ways of kinesthetically communicating with pain to develop new perceptions and living practices with the discomfort. As Sheets-Johnstone (2011) writes, we can cultivate new bodily understandings and capabilities as we kinesthetically unfold. On the other hand, my personal focus on movement emerged after starting to practice yoga and later with dance improvisation, through which I saw how I became new regarding myself and how I see the world. I became interested in movement-based interactions and what they do to us, and how they alter our perception. In addition, I was keen to explore how movement may influence our relationship with pain and the ways we live through it. Accordingly, this dissertation was initiated by my experience with chronic pain, enthusiasm for kinesthetic engagements, and my interactive textile practice. I situated this research at the intersection between the fields of HCI and interactive textile design. I adopted a soma design approach that emerged within HCI to inform the designing of soma extensions and to conduct this RtD project.

Based on my premises that suggested kinesthetically communicating with discomfort may promote somaesthetic awareness, I formulated the main research question of this research: *How may movement-based interactive textile wearables as soma extensions be designed to facilitate somaesthetic awareness of musculoskeletal chronic pain through mediating explicated interactions with it?* I examined this research question in three case studies that interrogated the particular aspects of it through the three sub-questions below.

1) *How may chronic pain experience inform the designing of soma extensions?*

2) How may soma extensions be designed to promote engaging bodily interactions in people with chronic pain?

3) How may soma extensions be designed to address the changing needs of bodies in chronic pain?

The first sub-question was answered by the first case study that provided insight into how chronic pain can be used as design material revealing visual and textual tools to elicit the felt experiences of pain as a design research methodological contribution. For this inquiry I cultivated first and second-person lived experiences of chronic pain that resulted in two iterations of a soma extension named *Squeaky/Pain* that illustrated promising potential for discomfoting interactions that could facilitate somaesthetic awareness. As a result, I offered tools to elicit first and second-person lived experiences and two design practice insights to be applied in designing soma extensions: 1) creating disturbing experiences in relation to the bodily discomfort in question, and 2) mimicking disturbing qualities through sound. In applying these two insights, non-habitual interactions can be created that may support new becomings of diseased bodies. The second sub-question was scrutinised in the second case study, where I conducted a cultural probe kit study to gain an in-depth understanding of the lived experiences of other diseased bodies in pain. The probe kit included the third iteration of the soma extension named *Caring Companion* that was used by the participants. This second case study provided design strategies for designing engaging soma extensions; in addition, it brought forth understandings of the somaesthetics of discomfort on three levels that were initiated from diagnosing the discomfort to cultivating self-caring practices. Finally, the third sub-question was examined in the third case study, where I harvested various qualities of pain through first-person explorations. This case study offered design with/for/through pain as a design research methodological approach and reformed the design strategies that emerged in the previous case study. It introduced the term *Kairos* – subjective time – as a necessary element in the cultivation of the somaesthetic awareness of pain. Finally, it presented the final iteration of the soma extension *Pain Creature* as a non-verbal communication of pain.

In examining the main research question, the three case studies provided methodological, theoretical, and artefact insights that helped me to build the design programme named *designing with discomfort*. *Designing with discomfort* is the meta-level contribution of this dissertation that informs the overlapping fields of HCI and interactive textile design. The focus of this programme is designing with/for/through bodily discomforts to facilitate the somaesthetic awareness of the discomfort in question. Acknowledging the hardship of removing chronic discomforts, *designing with discomfort* was built on the idea that bodies in discomfort require more-than-symptom-relieving approaches to live a better life with their diseased bodies. This design programme is a quest to find other ways of being and living with and through discomfort that is somaesthetics awareness. It advocated that through kinesthetically communicating with the explicated experiences of discomfort we can harvest other ways of being and be transformed with our diseased bodies. Therefore, *designing with discomfort* forms a call to intimately engage with agonising bodily phenomena to develop somaesthetic awareness.

It offered theoretical and methodological frameworks for designers who work within HCI, specifically in the field of embodied interactions, soma design and interactive wearables, and who wish to design for disturbing bodily experiences. First, it provided an extended understanding of the philosophy of somaesthetics by introducing three levels of the somaesthetics of discomfort – diagnosing the discomfort, understanding the discomfort, and corresponding with it through developing self-caring practices, finding new ways of living and being with it. In addition, it offered the creation of *Kairos*, where one can settle into bodily experiences for reflective dialogical conversations, as a basis for the somaesthetics of discomfort. It states that to engage with our diseased bodies we need time and space that is outside of objective time (*Chronos*) that is measured by clocks and is filled with schedules and appointments. We

need time that can expand as much as we need it to in order to reflectively interact with the discomfort. On the other hand, it proposed a design process that consists of two phases of somatic and material explorations within which designers can engage with the discomfort in question by *moving through*, *listening to*, and *thinking with discomfort*. In doing so, designers can establish a deeper insight into various qualities of discomfort and create explicated experiences of it through interactive artefacts. Additionally, it offered visual and textual elicitation tools to be used within this design process for the articulation of felt experiences of discomfort. Finally, *designing with discomfort* invited ethical and caring practices into the design research process. It suggested that when working with diseased bodies, we need to go beyond institutional ethical requirements. We need to sustain our attentive sensitivity towards ourselves, others, and the engagements between us and participants as well as between artefacts. By being attentive to what these situations might bring we can take ethically grounded caring actions.

Designing with discomfort acknowledges that the experience of discomfort is a unique individual experience and the somaesthetic journey of discomfort depends on the readiness, situation, and emotional capabilities of the diseased bodies. Therefore, *designing with discomfort* artefacts and ideals might not be suitable, effective, or appropriate for some bodies. In this regard, this dissertation and *designing with discomfort* is one of the many alternative ways of living and being with discomfort that offers a space for ignored, suppressed experiences of discomfort speculating other ways of living with them. On the other hand, I recognise that the experience of bodily discomfort is not solely a personal experience but rather it is interpersonal. As discussed previously, our lives are mostly organised within objective time full of schedules and meetings that involve engagement with other people. Discomforting experiences challenge these social interactions; for instance, when a diseased body in agony might have to participate in a meeting, or in the middle of a social gathering one may start to feel pain. Therefore, these social engagements influence how we experience and express our discomfort, how we make meanings of our diseased selves, and how we take care of our bodies in discomfort. In this dissertation, I explored how we can engage with discomfort on a personal level to improve our lives, which is one of the aspects of somaesthetically living with discomfort. In closing this dissertation, I suggest intersubjective relations of living with discomfort might be a future direction for exploring somaesthetic ways of living with discomfort that can extend the *designing with discomfort* programme.

Autoethnographic Interlude: Designer's Final Reflections on Pain

It is two weeks before the start of the first round of submitting this dissertation. I will first send it to my supervisors for the final checks before I send it in for the examination process. I did not have any sleep problems, but I decided to take a melatonin pill every night during this time to avoid any insomnia that would make me feel tired and prevent me from working. I started to feel distressed, I thought I was calm, but I think I was not. Not very surprisingly my IBS is flaring up so badly and it is really hard to concentrate on my writing in that situation, I don't know how to calm myself down. I still struggle with IBS but not like before, so my condition has improved a lot. Yet, in every flare-up I am afraid that it will stay forever at the agonising level, and I have to start my whole treatment process all over again which is like a nightmare for me. Five days later I stopped the melatonin pills because I didn't feel like I needed them. The first week of the last two weeks is finishing now and once again it hurts when I eat, and I feel a bit depressed. And this was not the end, probably both because of working in front of the computer for a long time and also because of the stress, I started to feel back pain. It is incredibly annoying to feel the existence of my neck, shoulders, and upper body, the existence of these parts is too heavy.

This is my last week, and I am trying not to skip my yoga routine, in stressful times especially. When I fight with time, I tend to skip my routine until I finish what I am doing. But this time I even practiced

yoga longer than usual hoping that it will also ease the tension and take away the heaviness of my bodily existence. I also do longer sessions because it helps to calm myself down. Otherwise, I feel restless in my body and cannot stop the agonising stressful thoughts. Despite my IBS flare-up and fear of a relapse, I did not cut myself out from foods that I was not able to eat before and I know they may cause flare-ups. I am now more aware that stress is a much stronger trigger than food. I feel like the longer yoga sessions are working, I am of course still stressed out but feeling a bit better and my IBS has started to get better as well. So, I guess I am doing something right. Although my back pain is now killing me, it also disrupts my sleep because I really cannot find a comfortable position to sleep where I won't feel the existence and heaviness of my upper body.

I now have three days before my submission, and since the morning I feel tense, heavy, and painful. I texted the masseur I was seeing for pain previously and managed to get an appointment for the evening. I guess till now after every important submission or event that triggered my back pain, I always received a massage. But this time I did not want to wait until I had finished what I was working on, but sought relief during the process.

It is now evening, I just left my massage appointment. I feel soft, light, and almost like I do not have a body which is an amazing feeling. I am so happy that I did this today, it does not only physically alleviate my tension, but I feel lighter in my mind too. I will not work this evening, just want to relax. I will meet with R. and enjoy my day. R. is also helping me to feel at ease.

The day before the submission, since the massage, my back has been better, and my IBS was better as well. The weather is amazing today, I will try to find time to enjoy it. I had a quick chat under the sun with Nesli. I tried to motivate myself to stay in the office a bit longer and then treat myself with my favourite food. Nesli is joining me for dinner, as we walk under the sun, I am enjoying the softness of my body and I do not even think or worry that my stomach might disturb me.

This is the final day before submission; I had a long energetic yoga session that woke my body up nicely. I am feeling good in my stomach and the back pain is not there anymore, I mean I still feel a little discomfort but not a tormenting sensation. It is early afternoon, and I am done with writing except for this final autoethnographic interlude. I decided to write this final reflection to illustrate where I am currently in my constantly evolving somaesthetic journey of discomfort. I wanted to illustrate how I transformed with my pain during the making of this dissertation. From what I wrote above it may seem like that nothing has changed because I am still in pain. But I would like to correct this illusion. As I have written several times, this dissertation did not focus on the alleviation of physical discomfort (directly), rather the focus was on finding new ways of living and being with our diseased bodies, learning to provide a place for discomfort to be expressed, communicated and understood.

In terms of back pain, previously I was stopping my yoga sessions to prevent possible injury or triggers, and as I wrote above, I never seek relief during stressful times but waited until I was done with the tasks that cause stress. Now I am aware of the fact that by seeking relief and caring for my body during these times, I can alleviate my agony and even increase my work efficiency. On the other hand, as I stated in my previous autoethnographic reflections, somaesthetically engaging with IBS is harder for me than the somaesthetic engagement with the back pain. For that reason, I spent a few days depressed with the fear of a persistent relapse when I had IBS flare-ups many days in a row. I am still struggling to accept the IBS but rather than cutting myself from foods and taking medications, I tried to engage in activities that can ease my stress; that is, spending time with the people I truly enjoy, appreciating a cup of tea under the sun, taking time to appreciate the upcoming spring and singing birds – specifically, each black bird I've seen – keeping up with my physical

exercises, thus, appreciating my body and eating the foods I like. In doing so, I improved my IBS even though it took two weeks to get there and even though I know that there are many relapses in the future ahead of me. This is where I am at the moment in my journey with my pain, I know that my attitude towards my conditions will fluctuate constantly between acceptance and feeling helpless, but I hope that I will be working towards cultivating self-caring practices.

KOKKUVÕTE

(Tekstiilist) laiendatud *soma*: kehalise ebamugavuse somaesthetika“ on praktikapõhine disainiuurimus, milles vaatlen, kuidas interaktiivsete kantavate tekstiilist esemete kui *soma*-laienduste abil suurendada somaesthetilist teadlikkust kehaliselt ebamugavatest kogemustest ehk arendada sensorset kehateadlikkust. Minu määratluse järgi on kehaline ebamugavus igapäevaelu segav krooniline seisund, näiteks fibromüalgia, depressioon, ärritunud soole sündroom või krooniline valu. Oma doktoritöös näitlikustan kroonilise valu abil, kuidas võiks disainida kehalise ebamugavusega koos, selle jaoks ja selle kaudu. Krooniline valu on kannataja igapäevaelu lahutamatu osa. Isegi kui valu ei ole iga päev ühesugune, kujundab see elu põhjalikult ümber. Valu võib käituda kui taltsutamatu koletis, mis loob kannataja ja maailma vahele barjääri, katkestades aja sujuva kulgemise ja muutes tuleviku arusaamatuks (Thomas & Johnson, 2000). Ühtlasi võib valu tekitada kannatajale füüsilisi piiranguid, mis võivad põhjustada hirmu ja vältimise mustrit, kus kannataja väldib teatud füüsilisi tegevusi kartuses, et need võivad valu vallandada (De Jong *et al.*, 2005; Vlaeyen & Linton, 2000). Nõnda võib valu mõjuda laastavalt harjumuspärasele eluviisile ja sundida inimest vastutahtsi muutma oma riietumis-, suhtlemis-, söömis- või liikumisharjumusi.

Kroonilist valu tuleks käsitleda mitte ainult füüsilise, vaid ka vaimse kogemusena. See samavõrd füüsiline kui ka psühholoogiline nähtus kujutab endast püsivat kehalist seisundit, millest vabanemine on raske, kui mitte võimatu. Seetõttu ei saa kroonilise valu leevendamine keskenduda ainult füüsiliste sümptomite ravile ja kergendamisele, vaid peaks ühtlasi toetama valuga hakkamasaamise vaimset teekonda. Hovey *et al.* (2018) leiavad, et kroonilisest valust tervenemine algab oma seisundiga leppimise ja valu poolt muundatud kehaga elama õppimisega. Leppimine on niisiis eeltingimus, et saaks alata transformatiivne teekond, mille käigus avastada uusi viise, kuidas valutavas kehas elada ja olla.

Doktoritöös ei otsi ma vastuseid, kuidas valu kõrvaldada või selle füüsilisi sümptomeid leevendada. Pigem otsin viise, kuidas valutavas kehas elada ja olla. Uurin, kuidas toetada keha ja valu dialoogi, et arendada kehalist teadlikkust kroonilisest valust. Valutav keha teab, et tal on valu, kuid see ei tähenda, et valu ohver ise on teadlik selle ebamugava kogemuse meeltega kogetavatest tahkudest. Kuna valu on püsiv krooniline seisund, võib keha selle kogemisega ära harjuda. Seetõttu väidan, et keha ja valu dialoogi toetamiseks tuleb keha ja valu vahel tekitada ebatavalisi kokkupuuteid, sest nii saab jõuda uute kehaliste arusaamadeni ja arendada valuga seotud kehateadlikkust. Ebatavalise kokkupuute loomiseks kasutan *soma*-laiendusi, mis vahendavad multisensorseid valukogemusi ja muudavad selle varjatud nähtuse käegakatsutavaks esemeks, mis võimaldab kehal end väljendada.

Soma-laienduste multisensorseid interaktsioonid põhinevad kinesteetilisel kaasamisel. Lähtudes arusaamast, et liikumise kaudu õpime mõistma maailma ja iseennast (Merleau-Ponty, 2002; Sheets-Johnstone, 2011; Shapiro, 2014; Wilson, 2002), on minu eesmärk toetada liikumisel põhineva interaktsiooni kaudu uute valuga seotud arusaamade ja tähenduste teket. Lisaks kasutan kinesteetilise interaktsiooni esilekutsumiseks heli, mis sümboliseerib valu tuntavaid omadusi. Helimärguanded, mida antakse sensorse tagasisidena liikumisele, võivad mõjutada keha aistinguid (Stanton & Spence, 2020). *Soma*-laienduse valmistamiseks kasutatud tekstiilide taktilised ja visuaalsed omadused toimivad valu füüsilise ilminguna. Niisiis võib öelda, et oma kuuldavate, taktiliste, visuaalsete ja kinesteetiliste omaduste kaudu kehastavad *soma*-laiendused kroonilist valu.

Doktoritöö peamine uurimisküsimus on järgmine: *Kuidas saab liikumispõhiseid interaktiivseid kantavaid tekstiilesemeid kui soma-laiendusi disainida nii, et need arendaksid somaesthetilist teadlikkust kroonilisest luu- ja lihasevalust, vahendades ja aidates selgitada selle interaktsiooni?* Kasutasin RtD (*research through design*, disainiuurimine) (Savic & Huang, 2014) lähenemisviisi ja rakendasin *soma*-

disaini meetodeid (Höök, 2018), et uurida disaini otstarbel lähemalt kroonilise valu põhjustatud ebamugavaid kehalisi aistinguid. Sealjuures kogusin enda ja teiste läbielatud valukogemusi, kasutades uurimismeetodina autoetnograafiat (Armitage, 2013; Given, 2008; Turner, 2013). Peamisele uurimisküsimusele vastamiseks jagasin selle kolmeks osaks ning sõnastasin nende põhjal alaküsimused, millele otsisin vastust kolmes juhtumiuuringus. Need küsimused on järgmised:

- 1) *Kuidas võib kroonilise valu kogemus aidata kaasa soma-laienduste disainile?*
- 2) *Kuidas saaks soma-laiendusi disainida nii, et need soodustaksid kroonilise valu all kannatavatel inimestel kaasahaaravat kehalist interaktsiooni?*
- 3) *Kuidas saaks soma-laiendusi disainida nii, et need vastaksid kroonilise valu all kannatava keha muutuvatele vajadustele?*

Need alaküsimused ei moodusta peamisest uurimisküsimusest lahusolevaid uurimusi. Pigem tuleks neid vaadelda doktoritöö põhitahkudena, mille käsitlemisel tehtud järeldused aitavad vastata peamisele uurimisküsimusele. Illustratsioon 1 kirjeldab uurimisprotsessi, kus iga juhtumiuuringu põhjal tehtud järeldused olid aluseks järgmisele alaküsimusele, mis viis järgmise juhtumiuuringuni. Kõik juhtumiuuringud aitasid mõista, kuidas disainida valuga koos, selle jaoks ja selle kaudu, ning avardasid ebamugavuse somaesteetika mõistet. Tehtud järelduste põhjal koostas disainiuuringute programmi „Ebamugavusest lähtuv disain“ (*Designing with discomfort*), mis on selle väitekirja peamine uurimispanus. Programmi eesmärk on mõista haiguse all kannatavate kehade kogemusi, et teisendada ebamugavust tekitavad implitsiitsed kogemused neis selgust loovateks disainiobjektideks ning arendada seeläbi somaesteetilist teadlikkust. Teisisõnu võib öelda, et püüan programmi abil leida teistsuguseid ebamugavusega koos, selle jaoks ja selle kaudu elamise, olemise, liikumise ja disainimise viise. Minu uurimus asetub interaktsioonidisaini (HCI) ning interaktiivsete tekstiilide valdkondade kokkupuutepunkti. Kutsun nendes valdkondades töötavaid teadlasi kujutlema teistsuguseid mooduseid, kuidas disainida ebamugavusega koos, selle jaoks ja selle kaudu ning kasutades siin uurimuses kirjeldatud kehastunud meetodeid.

Doktoritöö koosneb kuuest sisupeatükist, sissejuhatusest ja kokkuvõttest. Esimeses peatükis tutvustan uurimuse alustalasid, kirjeldades töös kasutatud uurimis- ja disainimetoodikat. Seejärel käsitlen teises peatükis töö aluseks olevaid filosoofilisi teooriaid. Kolmandas, neljandas ja viiendas peatükis tutvustan kolme juhtumiuuringut ning kuuendas peatükis kirjeldan doktoritöö metatasandi uurimispanust, programmi „Ebamugavusest lähtuv disain“. Allpool esitan igast peatükist põhjaliku kokkuvõtte.

1. peatükk. Metodoloogiline raamistik: somaatilise disaini uuringud

Artefakti loomine on disainipõhine uurimisviis, mille eesmärk on suurendada teadmust. Siin doktoritöös võimaldasid artefaktid ja *soma*-laiendused avada peamist uurimisküsimust ja kolme alaküsimust, mis aitasid kaasa programmi „Ebamugavusest lähtuv disain“ loomisele. Disainiuuringute väärtus ei seisne üksnes disainiteadmiste loomises – lisaks pakuvad nad ülevaadet uuritava nähtusega laiemalt seonduvatest ühiskondlikest ja filosoofilistest probleemidest. Disainiuuringutes, milles kasutatakse RtD (*research-through-design*, disainiuurimine) (Frayling, 1993) lähenemisviisi, kasutatakse artefakte analüüsi ning teoreetilise ja metodoloogilise edasiarenduse allikana (Salvic & Huang, 2014). RtD artefaktid on sageli abstraktsed ja kontseptuaalsed (Salvic & Huang, 2014) ning avardavad meie ettekujutust ja arusaama konkreetse uurimuse kontekstist. Siinse uurimuse puhul võimaldas mu tekstiilidisaineri taust põhjalikult uurida materjale, valmistamistehnikaid ja ekspressiivsete tajupõhiste materjalide kasutusviise. Juhiste, meetodite ja raamistikena kasutasin oma interaktiivses tekstiiliuurimuses veel interaktsioonidisaini (HCI), konkreetsemalt kehastunud disaini meetodit. Seega on valmistamine ja mõtlemine selles doktoritöös omavahel seotud ja teineteist aktiivselt mõjutavad protsessid.

Konkreetselt kasutasin kehastunud HCI meetodina *soma*-disaini (Höök, 2018), mille eesmärk on muuta esteetilised ehk tajukogemused igapäevaelu osaks ning edendada inimeste kehataju ja -teadlikkust. *Soma*-disainis omistatakse disainiprotsessis oluline roll kehastunud mõtlemisele. Disaineritel soovitatakse omandada omal käel kehalisi teadmisi ja lasta neil oma disainiprojekte inspireerida (Höök *et al.*, 2018). *Soma*-disainiprotsessides saab inspiratsiooniallikaks disaineri ja kasutajate läbielatud kogemus. Seetõttu kasutatakse uurimismeetodina autoetnograafiat, mis võimaldab koguda ja analüüsida tajutud kogemusi. Siinses uurimuses süvenesin kõigepealt omaenda kroonilise valu kogemusse, et kujundada põhjalikum arusaam valutunnetusest. Seejärel liikusin subjektiivsest uurimusest edasi teiste inimeste valukogemuse juurde. Omaenda ja teiste kogemuste uurimine toob nähtavale need tahud, mis jäävad valu puhul tavaliselt varjatuks. Teisest küljest iseloomustab *soma*-disaini arusaam, et kehateadlikkuse ja somaatiliste teadmiste arendamiseks tuleks harjumuspärane muuta ebataavaliseks (Höök, 2018). Nõnda on võimalik uuritavat nähtust uutmoodi tajuda ja jõuda uute arusaamadeni (Loke & Robertson, 2013). Höök (2018) kirjutab, et harjumuspärast võimaldavad ebataavaliseks muuta sellised somaatilised praktikad nagu Feldenkraisi tehnika, *tai chi*, jooga või tants. Kuna olen diplomeeritud joogaõpetaja ja tegelen improvisatsioonilise tantsuga, kasutasin harjumuspärastest olemis- ja liikumisviisidest väljamurdmiseks ning enda ja teiste osalejate kehateadlikkuse arendamiseks just neid tehnikaid. Teisisõnu kogusin ja analüüsisin omaenda ja teiste liikumises olevaid ja liikumisest tulenevaid valukogemusi.

Läbielatud kogemuste keerukuste tabamiseks kasutasin igas juhtumiuuringus erinevaid visuaalseid ja tekstilisi andmekogumisvahendeid. Esimene oluline andmekogumismeetod siinses uurimuses oli esemete valmistamine. Kordusel põhineva valmistamisprotsessi kaudu arendasin laiaulatuslikku arusaama *soma*-laienduste materiaaletest omadustest. Valmistamine näitab ja näitlikustab, kuidas muuta abstraktsed, implitsiitsed kogemused disainiprotsessi kaudu füüsilisteks artefaktideks, mis peegeldavad kehaliste kogemuste tajutavaid omadusi. Lisaks kasutasin kinesteetilisi harjutusi, et koguda 1) valu kogemise aistinguid ja 2) aistinguid, mis tekivad valutavas kehas *soma*-laiendustega kokkupuute ajal. Valu kogemise aistingud võimaldasid ammutada kontseptuaalseid teadmisi *soma*-laienduste disaini kohta, teised aistingud aitasid mul hinnata *soma*-laienduste mõju kehateadlikkusele. Visuaalse dokumentatsiooni vahendina kasutasin kehakaarte. Kehakaartide kasutamine on kunstipõhine tehnika, mis võimaldab kujutada inimeste elu ja kehalisi kogemusi (Gastaldo *et al.*, 2018). Kehakaarte saab kasutada vestluste hõlbustamiseks ja läbielatud kogemuste edasiandmiseks. Siinses töös on kasutatud kehakaartide eri vorme (tabel 1). Osa kehakaarte on joonistatud liikumisseanside käigus jäädvustatud fotodele, osa on loodud *soma*-laienduste disainiprintsiipide määratlemiseks ja laienduste hindamiseks. Olen kasutanud ka standardseid musta kontuuriga kehakaarte, kuna see oli käepärane lahendus, mis võimaldas teiste kohta teavet koguda ega nõudnud erinevalt näiteks fotole joonistatud kehakaardist eelnevat ettevalmistust. Viimaks kasutasin elusuuruses kehakaarte, kuhu kandsin üle oma keha valupunktid, et töötada nende põhjal välja *soma*-laienduse visuaalne disain, eeskätt selle vorm.

Mis puutub tekstilistesse vahenditesse, siis kasutasin oma subjektiivse, aga ka teiste osaliste valukogemuse edasiandmiseks uurimispäevikut. Kuna päevikusse tehakse ülestähendusi suhteliselt pika ajavahemiku jooksul, pakub see isiklikest kogemustest rikkalikku ülevaadet. Lisaks tegin videosalvestusi, et jäädvustada ja uuesti läbi vaadata kogemusi, mida liiguvad kehad tundsid nii liikumissessioonidel kui ka *soma*-laienduste hindamise käigus. Osalejate kogemuste lähemaks analüüsimiseks (kolmas ja neljas peatükk) tegin poolstruktureeritud intervjuud, mida ma ka salvestasin. Esimese juhtumiuuringu puhul kasutasin omaenda subjektiivsete kogemuste jäädvustamiseks enesekohast küsimustikku, mis matkis poolstruktureeritud intervjuud. Viimaks tegin teises juhtumiuuringus „kultuurisondiga“ disainiuuringu (*cultural probe kit*), mille abil õnnestus osalejatelt koguda disainiprotsessi inspireerivaid andmeid (Gaver *et al.*, 1999), milleks sedapuhku olid nende kroonilise valu kogemused. Dokumentatsiooni analüüsimiseks toetusin visuaalse narratiivi uurimise meetoditele, rakendades temaatilist analüüsi, narratiiviüuringut ja

videoanalüüsi. Need andmete analüüsimise vahendid aitasid mul selgitada uurimise käigus dokumenteeritud kogemuste tähendusi.

2. peatükk. Teoreetiline taust: somaesteetika lähtealused

Siin peatükis tutvustan lähemalt filosoofilisi teooriaid, millele doktoritöös tuginesin. Konkreetsemalt käsitlen somaesteetika teooriaid (Shusterman, 2008), taju fenomenoloogiat (Merleau-Ponty, 2002), liikumise fenomenoloogiat (Sheets-Johnstone, 2011) ja kehastunud tunnetust (Shapiro, 2014; Wilson, 2002). Nende teooriate ühisosa seisneb selles, et need mõtestavad inimese kohta maailmas keha kaudu. Keha määratletakse kui vahendit, mille kaudu kogeda ja ammutada välis- ja sisemaailma tähendusi. Neid teooriaid ei tohiks lahutada praktikast. Näiteks *soma*-disaini meetod põhineb eeskätt somaesteetikal, aga tugineb veel fenomenoloogiale ja kehastunud tunnetusele. Sedakaudu mõjutavad need teooriad ka sinise uurimuse käigus tehtud praktilisi samme. Seega on teooria ja praktika omavahel põimunud.

Fenomenoloogias leitakse, et me oleme maailmale avatud meelte kaudu (Merleau-Ponty, 2002) ning sensorset keha nimetatakse elatud kehaks (Gallagher, 1986; Merleau-Ponty, 2002). Somaesteetikas kasutatakse sama nähtuse tähistamiseks mõistet *soma* (Shusterman, 2008). Doktoritöös kasutan vaheldumisi sõnu *soma* ja *keha*, mis mõlemad osutavad inimese tajutavatele, kogemuslikele tahkudele. Keskendun töös sellele, kuidas mõtestame oma kehalisi liikumiskogemusi. Somaesteetikas on somaatiliste teadmiste täiendamise ja kogumise vahenditena pakutud selliseid liikumispraktikaid nagu Feldenkrais, jooga, *tai chi* jne (Shusterman, 2008). Somaesteetika ei püüa kehateadlikkusele läheneda mõtlemise kaudu, vaid tegeleb eelkõige kinesteetiliste kogemustega. Eesmärk on suurendada kehateadlikkust liikuvat ja tajuvat keha mõttetõesse kaasates. Ka kehastunud tunnetuses peetakse esmaseks tajuallikaks just tegevust, näiteks tegevuse ja taju ahel (*action-perception loop*) (Shapiro, 2019). Viitab sellele, et meie kehalised tegevused ja tajud mõjutavad üksteist ning on pidevas muutumises. Eelnevale tuginedes otsin oma uurimuses viise, kuidas suurendada kinesteetiliste juhtumiuuringute kaudu somaesteetilist teadlikkust kroonilisest valust ning disainin liikuva, tajuallikaks oleva kehaga koos, selle kaudu ja selle jaoks.

Somaesteetika eesmärk on suurendada somaatilisi teadmisi ja oskust kehalisi aistinguid väärtustada ning parandada seeläbi elukvaliteeti. Ma ei võrdsusta somaesteetilist teadlikkust objektiivses mõttes hea elukvaliteediga. Pigem leian, et somaesteetiline teadlikkus on subjektiivne ja kindla lõputa teekond, kus parema elukvaliteedi mõiste omandab igale inimesele erineva tähenduse. Doktoritöös käsitlen ebamugavustunde somaesteetilist teadvustamist kolmeetapilise teekonnana: 1) kroonilise füüsilise valu teadvustamine, 2) valu mõistmine ja 3) enesehooldepraktikate viljelemine. Selguse huvides olgu mainitud, et ma ei määratle somaesteetilist teekonda lineaarse protsessina, pigem kogeb valu kannatav keha kõiki neid etappe vahelduvas järjekorras.

Shusterman (2019) on kirjutanud, et valuga elamine õpetab meid leppima oma haavatavusega, ent jätkama sealjuures ravi otsimist. Valusate kogemuste omaksvõtmine ei tähenda leevenduseotsingutest loobumist, vaid hoopis tegelikkusele silma vaatamist ja enda võimestamist uute toimetulekuvõimaluste avastamiseks. Omaenda kroonilise valu kogemusele tuginedes nimetab Richard B. Hovey (2018) valu kingituseks, võimaluseks saada uueks koos valuga. Ta leiab, et valuga introspektiivselt suhestudes võime taastada ühenduse iseenda ja maailmaga. Väärt vahendiks selle kingituse tundmaõppimisel peab ta mõtisklust. Selleks, et mõtisklevalt ebamugavustundega suhestuda, on vaja aega ja ruumi, et häälestuda oma keha aistingutele, jõuda nende põhjal uute arusaamadeni ja astuda ebamugavustundega dialoogi. See protsess viib meid igapäevatoimetuste objektiivsest, kella juhitud ajast (*kronos*) subjektiivsesse, kogemuslikku aega (*kairos*). Seal saame luua ühenduse oma keha aistingutega (Brough, 2001; Hovey *et al.*, 2018). *Kairos* tähistab võimaluste ja lootuste hetke, tunnet, et elu liigub paremuse poole. See loob

võimaluse pidada kehaga sisukaid vestlusi ning leida koos valutava kehaga uusi vaatenurki. *Kairos*'e praktika kattub somaesthetika mõistega, mis käteb aistingute teadvustamist, mõistmist ja nendega suhestumist ning näeb eesmärgina enesehooldepraktikate viljelemist. Ebamugavuse somaesthetika juurde kuulub *kairos*'e hetkede loomine, et suhelda oma valutava kehaga ning tunda end noorema ja virgemana.

3. peatükk. Esimene juhtumiuuring: „Kriuksuv/valu“

Doktoritöö eesmärk oli uurida liikumispõhiste interaktiivsete kantavate tekstiilesemete ehk *soma*-laienduste kasutamise võimalusi, et suurendada teadlikkust kroonilise valu kogemustest. Eesmärk oli muuta tuntavad valuaistingud *soma*-laienduste disainielementideks, et hõlbustada kroonilise valu somaesthetilist teadvustamist ning otsida uusi viise kroonilise valuga elamiseks. Selleks pidin aru saama, kuidas koguda ja disainimaterjalina kasutada valu tuntavaid omadusi. Niisiis küsisin esimeses juhtumiuuringus, kuidas saaks kroonilise valu kogemus aidata kaasa *soma*-laienduste disainile. Uurisin seda küsimust kolmes etapis. Alustasin uurimisprotsessi omaenda kroonilise ülakehavalu uurimisega, et mõista selle subjektiivseid omadusi. Seejärel kujundasin saadud teadmiste põhjal *soma*-laienduse „Kriuksuv/valu“ (*Squeaky/Pain*) esialgse versiooni. Pärast seda korraldasin eri vaatenurkade kogumiseks osalejauuringu, milles osales kolm kroonilise valu all kannatavat isikut. See võimaldas *soma*-laiendust „Kriuksuv/valu“ täiustada ning seejärel oma keha peal katsetada. Juhtumiuuringus avastasin, kuidas kasutada disainiprotsessis nii iseenda kui ka teiste osalejate valuga seotud vaatepunkte, kasutades valu edukalt disainimaterjalina. Lisaks sain aimu sellest, kuidas *soma*-laiendused võivad arendada somaesthetilist teadlikkust. Selle küsimuse uurimist jätkasin ka järgmistes juhtumiuuringutes.

Esimeses etapis viisin läbi kolmenädalase liikumiseksperimenti, kus kordasin joogaharjutuste kava, mis aitas mul valu leevendada. Samal ajal pidasin päevikut (illustatsioonid 5 ja 6), kuhu oma muljed iga seansi järel kirja panin. Eksperimentiga lõpule jõudes töötasin päeviku uuesti läbi, et näha, mis aspektid seal esile kerkivad. Päeviku sissekannete põhjal koostasın somaatilise kogemuse kaardi (illustatsioon 7), mis kajastab mu liikumiseksperimenti eripärasid. Kaardil visualiseerisin valu asukohta, harjutuse käigus avarduvaid kehaosi, hingamisrütmi, venitusse kaasatud kehaosi ja valu tekitatud heli. Näiteks kirjeldasin päevikus, kuidas mu keha kriuksus joogaharjutuse ajal nagu vana puumaja või kuidas ma tundsin selgelt valu asukohta. Oma kogemuste üle mõtiskledes suutsin välja töötada disainiideed, mida sain kasutada *soma*-laienduse esimeses versioonis. Kuna uurimistöö eesmärk oli suurendada somaesthetilist teadlikkust valuga suhestumise kaudu, aitasin luua *soma*-laienduse kaudu selgust valu tajutavates tahkudes.

„Kriuksuv/valu“ sai disainitud interaktiivse kantava tekstiilesemena, mis pakkus nii heli ja liikumise vahelist interaktsiooni kui ka taktilist kogemust (illustatsioon 10). Minu päevikussekkannetest inspireerituna matkis artefakt valukogemust puidu kriuksumist meenutava heli kaudu, mis hakkas kõlama 30 sekundit pärast selle selgapanekut. Kogu interaktsioon kestis seitse minutit. Heli kinni keerata ei ole võimalik, ent aeglaselt liikudes saab hoida helitugevuse teatud tasemel. Selle disainitud interaktsiooniga lõi *soma*-laiendus viisi, kuidas valuga leppida ja selles liikuda. *Soma*-laienduse eesmärk oli kutsuda esile võõristustunne, et suurendada kandja liigutuste aeglustamise kaudu sensoorset kehateadlikkust. Teises etapis katsetasin prototüüpi kolme inimese peal, kes kannatasid kroonilise ülakehavalu all. Osalejauuring toimus neljas etapis poolteist tundi kestvate individuaalseanssidena. Esimene etapp koosnes põhjalikest poolstruktureeritud intervjuudest, mille käigus kasutasin joonistatud kehakaarte, et koguda teavet osalejate valukogemuse ja -taju kohta. Teise etapina viisin läbi hingamis- ja liikumisseansi, et suunata osalejate tähelepanu nende kehale. Kolmas etapp oli mittejuhitud liikumine *soma*-laiendusega, kus tutvustasin osalejatele laiendust ja andsin neile sellega suhestumiseks vabad käed. Viimases, neljandas etapis tegin teise poolstruktureeritud intervjuu, mille käigus kasutasin kehakaarte, et teada saada, millised olid osalejate valukogemused *soma*-laiendust kandes.

Soma-laiendus mõjutas osalejaid somaesteetilise teadlikkuse vahendamisel eri määral. Kõigi osalejate arvates suhestus „Kriuksuv/valu“ nende valukogemusega ja parandas nende valuga seotud kehateadlikkust. Osalejate tagasiside põhjal kujundasin *soma*-laienduse uue versiooni. Esimene versioon kattis kehal suuremat pinda ning hajutas mõne osaleja tähelepanu. Seetõttu kujundasin *soma*-laienduse teise versiooni nii, et see kattis üksnes valutava kohta. Lisaks ütlesid kaks osalejat, et *soma*-laiendusega kokkupuute ajal arvasid nad kuulvat mereranna häält, mis sümboliseeris valu leevenemist. Nende tagasiside andis mulle mõista, et leevendus kuulub valukogemuse juurde: seega kasutasin teise versiooni puhul lisaks puidu kriuksumise häälele ka meditatiivset *ambient*-heli. Sarnaselt esimese versiooniga pidi kandja ka teise laiendusega liikuma aeglaselt, et puidu kriuksumine ei valjeneks. Kui aga kõlama hakkas *ambient*-heli, pidi ta liikuma aeglaselt, et heli tugevneks. Katsetasin teist versiooni (illustratsioon 12) uuringu kolmandas ja viimases etapis oma keha peal. See katse näitas, et meeldivalt ja häirivalt mõjuv heli täiendasid teineteist, suunates kandja tähelepanu kehaliigutustele ja seeläbi implitsiitsetele kehakogemustele. Eri helid julgustasid kogema liigutusi eri viisidel ning võimaldasid tajuda keha uutmoodi.

Võib öelda, et uuring näitas valu kasutamise potentsiaali keha vastas kantavate interaktiivsete esemete disainimisel, osutades sellele, kuidas ebamugavate kogemuste selgitatud interaktsioon võib suurendada somaesteetilist teadlikkust. See valgustas peamise uurimisküsimusega seoses kolme asjaolu: 1) *soma*-laienduste võimalused ja kitsaskohad, 2) tööriistad nii isiklike kui ka jagatud kogemuste väljaselgitamiseks ja 3) mõju uudsete kehaliste interaktsioonide disainile. Arutelu *soma*-laienduse „Kriuksuv/valu“ võimaluste ja kitsaskohtade üle rõhutas, kui oluline on disainida artefakte, mis suhestuksid teiste inimeste valukogemustega, suunates neid oma ebamugavustundega tähelepanelikult tegelema ja rõhutades sünkroniseeritud tagasiside väärtust somaesteetilisele teadlikkusele. Tajutavate kogemuste jäädvustamiseks kasutasin visuaalseid ja tekstilisi meetodeid, mis aitasid valu teisendada interaktiivseks loominguks. Disaini puhul keskendusin ebamugavustundes selguse loomisele ja selle reprodutseerimisele heli kaudu, et kutsuda esile ebatavalisi kokkupuuteid, mis võimaldaks keha tajuda uutmoodi. Kuigi projekt näitlikustas ebamugavust tekitavate elementide potentsiaali valu somaesteetilise teadlikkuse suurendamisel, rõhutas see ühtlasi vajadust soodustada kehalist suhestumist *soma*-laiendustega. Seda teemat uurisin lähemalt teises juhtumiuuringus.

4. peatükk. Teine juhtumiuuring: „Hooliv kaaslane“

Teises juhtumiuuringus vaatlesin, kuidas saaks *soma*-laiendusi disainida nii, et need soodustaksid kroonilise valuga inimestel kaasahaaravat kehalist interaktsiooni. Esimeses juhtumiuuringus süvenesin kolme nädala jooksul omaenda valukogemusse ja kogusin ühepäevase uuringu käigus teiste osalejate valukogemusi. Teises juhtumiuuringus püüdsin põhjalikumalt aru saada teiste inimeste kogemustest, kes on suhteliselt pika perioodi jooksul kannatanud luu- ja lihasevalu all. Selleks tegin viie valu käes kannatava inimesega kolme nädala jooksul „kultuurisondiga“ disainiuuringu, kus uurisin *soma*-laienduse kolmandat versiooni. Disainiuuringu komplekt sisaldas nii füüsilisi kui ka digitaalseid esemeid (illustratsioon 14). Füüsilised esemed olid *soma*-laiendus, päevik, 12 kehakaarti, 12-sõnalised loendid, mis sisaldasid 42 valuväljendit, värvilised viltpliiatsid, plastiliin, kalender ja komplekti kasutusjuhend. Digitaalsed esemed olid kaks YouTube'i üles laaditud joogavideot, üks üla- ja teine alakehavalu jaoks, ning helifail.

Osalejatel paluti salvestada helifail mobiiltelefoni ja asetada helifaili esitav mobiiltelefon *soma*-laiendusse (vt illustratsiooni 15). Seejärel paluti neil kanda *soma*-laiendust, asetades see valutava piirkonna kohale (nt puusale või alaseljale) ning järgida YouTube'i joogaharjutuste kava. Osalejatel oli võimalus valida harjutuskava valu asukoha järgi. Pärast harjutuskava läbimist koos *soma*-laiendusega julgustati neid kasutama päevikut, sõnaloendeid, plastiliini ja teisi vahendeid, et väljendada ja jäädvustada harjutuse ajal

kogetud aistinguid ja kogemusi. Kolme nädala möödudes kohtusin osalejatega uuesti ja tegin nendega poolstruktureeritud intervjuu, kus palusin neil mõtiskleda oma jäädvustuste ja uuringu käigus saadud kogemuste üle. Seejärel analüüsisin osalejate kirjeldusi temaatilise analüüsi abil, et saada aru *soma*-laienduse kaasahaaravatest omadustest, võimalustest ja kitsaskohtadest. Temaatilises analüüsis tuginesin tekstiliste kirjelduste andmetele ja keskendusin kuulmise, puute ja kantavusega seotud interaktsioonidele. *Soma*-laienduste kuuldavad omadused mängisid väga tähtsat rolli nii kannatuste tekitamisel kui ka valu leevendamisel, kusjuures osalejad kogesid häirivat heli valu matkivana, meeldivat heli aga rahustavana. Taktiilsed omadused seevastu teravdasid osalejate teadlikkust lokaalsest valust ja pakkusid valulike kogemuste ajal tuge, aidates osalejatel harjutusele keskenduda. Lisaks ilmnes uuringus mõtisklusvahendite tähtsus osalejate kogemuste kogumisel ja eneseteostuse soodustamisel. Lõpuks selgusid analüüsist mõningad märksõnad, mis annavad ülevaate sellest, kuidas *soma*-laiendus saaks võimaldada kaasahaaravaid interaktsioone: koosolemistunne, improvisatsioon, ebamugavustundega suhestumine, kehaliste kogemuste ajutine iseloom ja somaatiliste teadmiste ülekandmine igapäevaellu. Need märksõnad näitasid, kuidas osalejad *soma*-laiendusega suhestusid, ja aitasid välja kujundada neli rakendatavat disainistrateegiat kaasahaaravate kehaliste interaktsioonide disainimiseks.

Need disainistrateegiad on: 1) koosolemistunde loomine, 2) ebamugavuse esiletoomine, 3) improvisatsiooniruumi loomine ja 4) somaatiliste tegevuste toetamine igapäevaelus. Esimese strateegia eesmärk on luua ühtekuuluvustunne, mis toetaks kehalisi kokkupuuteid ja somaesteetilisi interaktsioone. Teine strateegia keskendus ebamugavuses selguse loomisele keha vastas kantavate esemete kaudu ja ebamugavusega seotud multisensorsete interaktsioonide loomisele, et inimestel oleks võimalik valu teistmoodi kogeda ja kirjeldada. Kolmas strateegia soovib kasutada artefaktide puhul kujutlusvõimet elavdavaid elemente. See tähendab, et liikumisel põhinevate interaktsioonide range juhendamise asemel jäeti ruumi loomingulisteks kokkupuudeteks, kus artefaktidega varustatud kehad saavad mõtestada oma kogemusi improviseeritud liigutuste pidevas voos. Viimane strateegia pakkus disaineritele võimalust lisada oma loomingusse konkreetseid ja praktilisi elemente, mida kasutajad saavad igapäevaelus vahetult rakendada.

Samas avardas see juhtumiuuring kroonilise valuga seotud somaesteetilise teadlikkuse mõistet, tuues välja selle kolm tasandit, kus esimene tasand on valu teadvustamine, teine tasand käsitleb valu ja selle all kannatava keha vajaduste mõistmist, kolmas aga keskendub enesehooldepraktikatele. Teisisõnu määratlesin kolm somaesteetilise teadlikkuse tasandit, alates kehaliste kogemuste teadvustamisest kuni vastava suhte loomiseni valuga. Teadlikkuse kujunemise eelduseks on kehaliste piirangute aktsepteerimine. Käsitlesin somaesteetilist teadlikkust mitmekihilise teekonnana, mille kolmas tasand ei ole sugugi lõplik sihtpunkt. Pigem pean seda pideva uuenemise teekonnaks, mis kulgeb mittelineaarselt eri kihtide vahel.

Kokkuvõtteks võib öelda, et kirjeldatud juhtumiuuring andis ülevaate sellest, kuidas saab kaasahaaravaid kehalisi interaktsioone disainida somaesteetilise teadlikkuse edendamiseks. Lisaks tõi uuring esile kehaliste kogemuste ajutise iseloomu ja asjaolu, et need on isegi kroonilise valu puhul pidevas muutumises. Arusaam valukogemuste muutlikkusest andis mõista, et *soma*-laienduste puhul on somaesteetilise teadlikkuse arendamiseks vajalik pöörata tähelepanu ajalisele mõõtmele. Nõnda andis „Hooliv kaaslane“ (*Caring Companion*) tõuke uuele uurimissuunale, mida käsitlen kolmandas juhtumiuuringus.

5. peatükk. Kolmas juhtumiuuring: „Valuolend“

Ehkki krooniline valu saadab inimest igapäevaelus pidevalt, muutub selle intensiivsus ja iseloom hetkest hetkesse. Ajalise mõõtme tunnistamine on valu mõju mõistmiseks ülioluline. Valu on muutlik kogemus,

mida mõjutavad mineviku läbielamised ja tuleviku hirmud, ning iga valuhetk on ainulaadne. Valu nüansirikkuse käsitlemiseks süüvisin küsimusse, *kuidas saaks soma-laiendusi disainida nii, et need vastaksid kroonilist valu kannatava keha muutuvatele vajadustele*. Niisiis püüdsin selles juhtumiuuringus koguda ja kasutada *soma*-laienduse disainimiseks erinevaid valukogemusi. Selleks tegin iseendaga uuringu, et tuua esile omaenda kroonilise valu muutlikke tahke. „Valuolendi“ (*Pain Creature*) disainiprotsess kulges kahes etapis: 1) somaatilised otsingud ja 2) materjaliuuringud. Selleks et disainida valuga koos, valu jaoks ja valu kaudu, kasutasin uurimismeetodina valust läbi liikumist, valu kuulama õppimist ja selle mõttetõesse kaasamist.

Disainiprotsess algas nädalase improvisatsioonilise liikumispraktikaga, kus „kuulasin“ liikumise ajal oma valusid. Nädala jooksul tegin neli liikumisseanssi ja salvestasin need kõik videona. Pärast iga seansi kirjutasin üles mõned märksõnad, mis mu kogemust kirjeldasid. Illustratsioon 24 kujutab esimese nelja päeva märksõnu. Valust läbi liikumise ja selle kuulama õppimise eksperimendile järgnes valu mõttetõesse kaasamine, kus vaatasin uuesti läbi oma videosalvestised, et üles tähendatud märksõnade põhjal oma kogemust mõtestada. Valu mõttetõesse kaasates töötasin välja kuus valumõõdet, mis kajastusid ka *soma*-laienduses. Need olid: 1) koorem, 2) tektoonilised laamad, 3) lained, 4) soe puudutus, 5) ihu ja 6) tühi. Hilisemas etapis asusin uurima materjali ehk vaatlema tuvastatud valumõõtmete taktiilseid ja kuuldavaid omadusi (tabel 5). Saadud teadmiste najal asusin looma materjalinäidiseid ja liikusin koos nendega, et hinnata nende kogemuslikke omadusi. Helikujunduses tegin koostööd helikunstnikuga, kellega disainisime artefakti auditiiivse tagasiside ja interaktsiooniomadused. Hiljem mõistsime, et tehnilistel põhjustel saame rakendada ainult viit mõõdet. Otsustasin ära jätta kuuenda, nähtamatu komponendi „tühi“, mille eesmärk oli vahendada üksnes keha valuliku piirkonna heli. Kuna doktoritöö eesmärk oli tegelda valu väliste interaktsioonidega nii heli kui ka materjalide kaudu, otsustasin jätkata ainult valu väliste komponentidega, et uurimus oleks terviklik.

Lisaks oma subjektiivse valu uurimisele kasutasin „Valuolendit“ disainides teise juhtumiuuringu käigus avastatud disainistrateegiaid. Selle tulemusena disainisin *soma*-laienduse, mis aitab selgitada valu erinevaid omadusi (illustratsioon 26). Selles *soma*-laienduste lõplikus versioonis on iga valukomponent artefaktiga püsivalt ühendatud. Samas on võimalik üksikuid komponente interaktsiooni kandvast mikrokontrollerist lahti ühendada. Seega saavad kehad valida, milliste valumõõtmega kokku puutuda. Katsetasin *soma*-laienduse lõplikku versiooni oma kehal. Otsustasin, et kasutan seda nädala jooksul nii tihti, kui vajalikuks pean. Kokku kasutasin seda kolm korda, kusjuures iga seanss oli eri pikkusega ja hõlmas eri valumõõtmey. Filmisin oma interaktsiooni ja tegin pärast iga kasutuskorda oma kogemuse kohta märkmeid. Oma jäädvustuste põhjal analüüsisin oma elu koos „Valuolendiga“, et uurida *soma*-laienduse võimalusi ja kitsaskohti. Artefakti taktiilsus ja rikkalik auditiiivne tagasiside aitasid kaasa tugeva interaktsiooni tekkele. Lisaks aitas võimalus valida, milliste valumõõtmega kokku puutuda, reageerida ja keskenduda konkreetsetele aistingutele, mis iga kasutuskorra vajalikuks tegid.

Teisest küljest andis „Valuolendi“ disainiprotsess metodoloogilise ülevaate, kuidas *disainida* valuga koos, valu jaoks ja valu kaudu. See protsess põhineb valu tuntavate omaduste – mitte üksnes häirivate, vaid ka leevendavate ja nende vahepealsete – kogumisel, analüüsimisel ja esilekutsumisel. Need metodoloogilised avastused pakkusid somaatilisi ja materiaalseid teadmisi keha vastas kantavate esemete disainimise protsessi kahe peamise etapi kohta ebamugavuse kontekstis. Disainer saab disainiprotsessi hõlbustamiseks valust läbi liikuda, seda kuulama õppida ja mõtteprotsessi kaasata. Lisaks täiendasin disainiprotsessile mõeldes teises juhtumiuuringus esile kerkinud disainistrateegiaid kahe uue strateegiaga: 1) *ajutisusest lähtuv disainimine* ja 2) *igapäevaelus ruumi tegemine kairis'ele*. Ühendasin varem välja pakutud strateegia – *somaatiliste tegevuste toetamine igapäevaelus* – äsja esitatud teise strateegiaga, sest need kattuvad omavahel. Muudetud strateegiad koosnevad viiest disainitoimingust: 1) *koosolemistunde*

loomine, 2) *ebamugavuse esiletoomine*, 3) *improvisatsiooniruumi võimaldamine*, 4) *ajutisusest lähtuv disainimine* ja 5) *igapäevaelus ruumi tegemine kairos'ele (kvaliteetaeg)* (tabel 6). *Ajutisusest lähtuva disainimise* puhul tuleks silmas pidada, et arvestades valu igapäevast muutlikkust ja selle mõju kehale, peaksid valukogemuse edasiandmiseks mõeldud disainiesemed püüdma tabada valu erinevaid ilminguid ja kirjeldama selle mitmetahulisi mõõtmeid võimalikult laiaulatuslikult. *Igapäevaelus kairos'ele ruumi tegemise strateegia* viitas sellele, et *soma*-laiendused peavad toetama põhjalikku teadlikkust kehakogemustest ning looma koha, kus saaks *kairos'*e ajal tegeleda vaatluse ja eneserefleksiooniga.

Tänu *kairos'*e kaasamisele andis juhtumiuuring teadmisi kehalise ebamugavuse somaestetikast. Valu kontekstis oma elu ümberkujundamise protsess sõltub sobiva hetke leidmisest, mis on iga inimese puhul ainulaadne. Tunnistades nende kogemuste ajutist olemust, ei ole oma elu ümberkujundamine koos valuga lineaarne teekond, vaid kulgeb mööda erinevaid omavahel seotud trajektoore, kus tagasilöögid on teekonna lahutamatu osa. Kui on loodud võimalused kehaliste aistingutega kogetavateks reflektiivseteks ja dialoogilisteks interaktsioonideks, hõlbustab *kairos* somaestetilise teadlikkuse arengut ja muutumist. Viimaks toob juhtumiuuring esile *soma*-laienduse kui valu mitteverbaalse väljendamise vahendi. Valu võib olla raske tekstiliste vahenditega väljendada, samas kui loomingulised meetodid, nagu joonistamine, liikumine ja heli, võivad aidata haigusest vaevatud kehal oma kannatusi edasi anda. Niisiis on „Valuolend“ valu multisensoorne väljendaja, mis aitab seda ebamugavat kogemust loomingulisel viisil edasi anda.

6. peatükk. Uurimuspanus: uus uurimisprogramm „Ebamugavusest lähtuv disain“

Doktoritöös otsisin vastust järgmisele uurimisküsimusele: *Kuidas saaks liikumispõhiseid interaktiivseid kantavaid tekstiilesemeid kui soma-laiendusi disainida nii, et need arendaksid somaestetilist teadlikkust kroonilisest luu- ja lihasevalust, vahendades ja aidates selgitada selle interaktsiooni?* Peamisele uurimisküsimusele vastamiseks tegin kolm juhtumiuuringut, millest igaühes uurisin erinevat alaküsimust. Need juhtumiuuringud võimaldasid mul välja töötada meetodid, mille abil valmistada keha vastas kantavaid interaktiivseid esemeid, mis soodustaksid somaestetilist suhestumist valuga. Ühtlasi sain juhtumiuuringute põhjal teada, milliseid disainistrateegiaid nende esemete loomiseks kasutada. Peale selle andsid juhtumiuuringud võimaluse avardada valu kontekstis somaestetilise teadlikkuse filosoofilist käsitlust. Tulemused näitasid, et liikumisel põhinevad multisensoorsed interaktiivsed kantavad tekstiilid, mille taktilised, nähtavad ja kuuldavad elemendid aitavad selgust luua valu erinevates tahkudes, võivad suurendada kroonilise valuga inimeste somaestetilist teadlikkust. Juhtumiuuringud keskendusid peamiselt kroonilise valu somaestetikale, aga nende käigus saadud metodoloogiliste, disainialaste ja teoreetiliste teadmiste põhjal saab teha üldistusi kehalise ebamugavuse somaestetika kui sellise kohta. Juhtumiuuringute tulemusel joonistus välja disainikäsitus, mida ma nimetan *ebamugavusest lähtuvaks disainiks*, ning sai alguse disainiuuringute programm, mis on kooskõlas Redströmi seisukohaga disainiteooria arendamisest. Somaestetika teooriale tugineva disainikäsitluse keskmes on somaestetilise teadlikkus kehalise ebamugavuse kontekstis.

Programm „Ebamugavusest lähtuv disain“ põhineb arusaamal, et kehalise ebamugavuse all kannatavatele inimestele ei piisa sümptomite leevendamisest, vaid vaja on terviklikku käsitlust, mis võimaldaks neil haigusest hoolimata parandada oma elukvaliteeti. Pelgalt sümptomite leevendamise asemel on selle käsitluse puhul oluline oma olukorraga leppida ja õppida ebamugavusega elama. See on teekond, mida ebamugavuse disaini kontekstis mõtestatakse kui somaestetilise teadlikkuse suurendamist. Niisiis võib järeldada, et keha vastas kantavad esemed, mis võimaldavad suhestuda kehalise ebamugavuse väliste avaldumisvormidega, võivad olla sel teekonnal abiks. Disaini mõistetakse kui kehalise ebamugavuse uurimist selle eri mõõtmete kaudu ja nende kogemuste väljendamist disainiesemetes. Sisuliselt on

ebamugavusest lähtuva disaini põhimõtte *disainida kehalise ebamugavusega* koos, selle jaoks ja selle kaudu, et edendada somaesteetilist teadlikkust.

Kõnealune uurimisprogramm on katse kujutleda alternatiivseid olemasolu-, elu- ja disainikäsitlusi, pidades silmas krooniliste haigustega inimeste vajadusi ja keskendudes häirivate kogemuste leevendamise või allasurumise asemel hoopis nende väljendamisele. Programm põhineb ebamugavusega seotud subjektiivsete kogemuste kogumisel ja analüüsimisel ning nende kasutamisel disainiinspiratsiooni allikana. Ebamugavusest lähtuva disaini mõiste on kasutusele võetud selleks, et luua kroonilise ebamugavuse all kannatavatele inimestele disainiruum, kus küsimärgistada kehalise ebamugavuse kohta tavapäraselt käibivaid käsitlusi. Programmi „Ebamugavusest lähtuv disain“ disainiteooria heidab valgust keha vastas toimuvate ja kehalise ebamugavusega seotud interaktsioonide loomisele. Programm on minu uurimispanus disainiuuringute valdkonda, eriti sellesse uurimissuunda, kus puutuvad kokku interaktsioonidisain (HCI) ja interaktiivsed tekstiilid. HCI kontekstis on ebamugavusest lähtuv disain kooskõlas kehastunud disaini käsitlustega, ammutades inspiratsiooni *soma*-disaini teooriast, mis keskendub oma somaatilise tundlikkuse arendamisele disaini eesmärgil. Minu programm arendab seda mõtet edasi ning pöörab tähelepanu just ebamugavusega seotud tajulise tundlikkuse arendamisele, et toetada kroonilise ebamugavuse all kannatavate inimeste elu. „Ebamugavusest lähtuv disain“ rakendab kordustel põhinevat disainiprotsessi, mis põimib disainiesemete loomisel saadud mitmekesised kogemused keerukaks tervikuks.

Minu uurimispanus väljendub programmi jaoks välja töötatud metodoloogilistes vahendites, mis võimaldavad disainida ebamugavusega koos, selle jaoks ja selle kaudu, ning ebamugavuse somaesteetika filosoofilise käsitluse avardamises. Programmi käsitlust iseloomustab ka arusaam, et ebamugavusega tegeledes tuleks juurutada eetilist ja hoolivat suhtumist enda ja teiste disainiprotsessi kaasatud inimeste kehasse. Oma somaatiliste kogemustega tegelemine võib aidata kujundada inimeses välja eetilise ja hooliva tunnetuse ning arendada temas tajude väärtustamise oskust (Popova *et al.*, 2022). Ebamugavusest lähtuva disaini mõiste rajaneb arusaamal, et disainiprotsess peaks alguse saama disaineri isiklikest somaatilistest otsingutest. Need avavad võimaluse kehalisest ebamugavusest põhjalikumalt aru saada, aga arendavad ka eetilist ja hoolivat suhtumist iseendasse ja teistesse. Ebamugavusega seotud isiklike kogemuste lahkamine võib panna disainerid haavatavasse olukorda, sest jagatakse ja paljastatakse ju omaenda elu. See haavatavus võib soodustada mõtisklusi eetiliste valikute teemal, mis aitavad suurendada eetiliste kaalutluste tähtsust suhtluses teistega. Disainerid peaksid suutma ette näha osalejauuringutes tekkida võivaid erilisi olukordi, et teadvustada uuringutega kaasnevat emotsionaalset tööd. Kõiki inimkehaga töötamisel tekkida võivaid stsenaariume ei ole võimalik ette näha, kuid disainerid peaksid säilitama selge teadlikkuse nii endast kui ka uuringus osalejatest, et olla valmis reageerima olukordadele, mis nõuavad viivitamatut, eetiliselt põhjendatud hoolt.

Niisiis on programmi „Ebamugavusest lähtuv disain“ disainiprotsessis disaineri ülesandeks ebamugavusest läbi liikuda, seda kuulama õppida ja mõttetõesse kaasata, et koguda, analüüsida ja fikseerida oma ebamugavuse läbielatud tahke ja neid siis disainis rakendada. Selles disainiprotsessis saab eristada kahte järku: *somaatilised* ja *materjaliotsingud*. Somaatiliste otsingute käigus saab kasutada teabekogumisvahendeid, mis võimaldavad ammutada teadmisi enda ja teiste ebamugavusaistingute kohta. Materjaliotsingute järk keskendub disainiesemete loomisele ning koosneb viiest disainistrateegiast, mis võimaldavad välja arendada keha vastas kantavaid meelihaaravaid esemeid, mis edendavad ebamugavuse somaesteetikat. Lisaks on programmis oluline kaasata ebamugavusest lähtuva disaini uurimisprotsessi eetika ja hool kui generatiivsed mõisted. Neid põhimõtteid tuleks pidevalt arendada ja praktikas kasutada.

Niisiis uurisin oma doktoritöös, kuidas ebamugavuse poolt esile kutsutud interaktsioonid võiksid soodustada somaesteetilist teadlikkust. Pakkusin välja disainiprogrammi, mis on üks võimalik viis, kuidas

disainida ebamugavusega koos, selle jaoks ja selle kaudu. Edaspidi võiks programmi „Ebamugavusest lähtuv disain“ edasiarendamiseks uurida intersubjektiivseid suhteid ebamugavusega elamise kontekstis.

REFERENCES

- Abrahamson, D., & Lindgren, R. (2014). Embodiment and Embodied Design. In R. K. Sawyer (Ed.), *The Cambridge Handbook of the Learning Sciences* (2nd ed., pp. 358–376). Cambridge University Press. <https://doi.org/10.1017/CBO9781139519526.022>
- Andersen, K. (2013). *Making Magic Machines*. KTH Royal Institute of Technology.
- Andringa, T., & Lanser, J. (2013). How Pleasant Sounds Promote and Annoying Sounds Impede Health: A Cognitive Approach. *International Journal of Environmental Research and Public Health*, 10(4), 1439–1461. <https://doi.org/10.3390/ijerph10041439>
- Angelucci, A., Cavicchioli, M., Cintorrino, I. A., Lauricella, G., Rossi, C., Strati, S., & Aliverti, A. (2021). Smart Textiles and Sensorized Garments for Physiological Monitoring: A Review of Available Solutions and Techniques. *Sensors*, 21(3), 814. <https://doi.org/10.3390/s21030814>
- Armitage, S. (2013). Introduction: Storying Life and Lives. Short, N.P., Turner, L. Grant, A. (eds) *Contemporary British Autoethnography*.
- Barad, K. (2014). Diffracting Diffraction: Cutting Together-Apart. *Parallax*, 20(3), 168–187. <https://doi.org/10.1080/13534645.2014.927623>
- Barrett, E., Conroy, C., Corcoran, M., Sullivan, K. O., Purtill, H., Lewis, J., & McCreesh, K. (2018). An evaluation of two types of exercise classes, containing shoulder exercises or a combination of shoulder and thoracic exercises, for the treatment of nonspecific shoulder pain: A case series. *Journal of Hand Therapy*, 31(3), 301–307. <https://doi.org/10.1016/j.jht.2017.10.011>
- Baxter, P., & Jack, S. (2015). Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative Report*. <https://doi.org/10.46743/2160-3715/2008.1573>
- Bell, G., Blythe, M., & Sengers, P. (2005). Making by making strange: Defamiliarization and the design of domestic technologies. *ACM Transactions on Computer-Human Interaction*, 12(2), 149–173. <https://doi.org/10.1145/1067860.1067862>

- Bellamy, N. (2002). Rhythmic variations in pain, stiffness, and manual dexterity in hand osteoarthritis. *Annals of the Rheumatic Diseases*, 61(12), 1075–1080. <https://doi.org/10.1136/ard.61.12.1075>
- Bendelow, G. A., & Williams, S. J. (2008). Transcending the dualisms: Towards a sociology of pain. *Sociology of Health & Illness*, 17(2), 139–165. <https://doi.org/10.1111/j.1467-9566.1995.tb00479.x>
- Benford, S., Greenhalgh, C., Giannachi, G., Walker, B., Marshall, J., & Rodden, T. (2012). Uncomfortable interactions. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 2005–2014. <https://doi.org/10.1145/2207676.2208347>
- Beuthel, J. M., & Wilde, D. (2017). Wear.x: Developing Wearables that Embody Felt Experience. *Proceedings of the 2017 Conference on Designing Interactive Systems*, 915–927. <https://doi.org/10.1145/3064663.3064799>
- Biro, D. (2011). Redefining pain. *Palliative and Supportive Care*, 9(1), 107–110. <https://doi.org/10.1017/S1478951510000593>
- Botlorff, J. (1991). *The lived Experience of Being Comforted by a Nurse*. Phenomenology + Pedagogy (Vol. 9, pp. 237-252)
- Boudreau, S. A. (2018). Digital body maps reinvent the way we perceive and discuss pain and discomfort. *Physiotherapy Quarterly*, 26(4), 1–3. <https://doi.org/10.5114/pq.2018.79739>
- Bourke, J. (2017). *The Story of Pain: From Prayer to Painkiller*. Oxford University Press.
- Brandt, E., & Binder, T. (2007). *Experimental Desing Research: Genealogy—Intervention—Argument. I.*
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589–597. <https://doi.org/10.1080/2159676X.2019.1628806>
- Bresin, R., Papetti, S., Civolani, M., & Fontana, F. (2010). Expressive Sonification of Footstep Sounds. *Proceedings of Interactive Sonification 2010*.
- Brough, J. B. (2001). Temporality and Illness: A Phenomenological Perspective. In S. K. Toombs (Ed.), *Handbook of Phenomenology and Medicine* (Vol. 68, pp. 29–46). Springer Netherlands. https://doi.org/10.1007/978-94-010-0536-4_2

- Burrows, A., Mitchell, V., & Nicolle, C. (2015). Cultural probes and levels of creativity. *Proceedings of the 17th International Conference on Human-Computer Interaction with Mobile Devices and Services Adjunct*, 920–923. <https://doi.org/10.1145/2786567.2794302>
- Campo Woytuk, N., Søndergaard, M. L. J., Ciolfi Felice, M., & Balaam, M. (2020). Touching and Being in Touch with the Menstruating Body. *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–14. <https://doi.org/10.1145/3313831.3376471>
- Cochrane, K. A., Mah, K., Ståhl, A., Núñez-Pacheco, C., Balaam, M., Ahmadpour, N., & Loke, L. (2022). Body Maps: A Generative Tool for Soma-based Design. *Sixteenth International Conference on Tangible, Embedded, and Embodied Interaction*, 1–14. <https://doi.org/10.1145/3490149.3502262>
- Coelho, A., Parola, V., Escobar-Bravo, M., & Apóstolo, J. (2016). Comfort experience in palliative care: A phenomenological study. *BMC Palliative Care*, 15(1), 71. <https://doi.org/10.1186/s12904-016-0145-0>
- Correll, D. J., & Kissin, I. (2017). Publication-Based Academic Interest in Drugs and Techniques for Treatment of Postoperative Pain, 1975-2015. *Journal of Anesthesia History*, 3(4), 122–127. <https://doi.org/10.1016/j.janh.2017.08.001>
- Couser, G. T. (2018). Illness, Disability, and Ethical Life Writing. *CLCWeb: Comparative Literature and Culture*, 20(5). <https://doi.org/10.7771/1481-4374.3482>
- Crawford, L. (1984). Viktor Shklovskij: Differance in Defamiliarization. *Comparative Literature*, 36(3), 209. <https://doi.org/10.2307/1770260>
- Cutter, B., & Tye, M. (2011). Tracking Representationalism and the Painfulness of Pain. *Philosophical Issues*, 21(1), 90–109. <https://doi.org/10.1111/j.1533-6077.2011.00199.x>
- da Costa, B. R., Reichenbach, S., Keller, N., Nartey, L., Wandel, S., Jüni, P., & Trelle, S. (2017). Effectiveness of non-steroidal anti-inflammatory drugs for the treatment of pain in knee and hip osteoarthritis: A network meta-analysis. *The Lancet*, 390(10090), e21–e33. [https://doi.org/10.1016/S0140-6736\(17\)31744-0](https://doi.org/10.1016/S0140-6736(17)31744-0)

- De Jong, J. R., Vlaeyen, J. W. S., Onghena, P., Goossens, M. E. J. B., Geilen, M., & Mulder, H. (2005). Fear of Movement/(Re)injury in Chronic Low Back Pain: Education or Exposure In Vivo as Mediator to Fear Reduction? *The Clinical Journal of Pain*, 21(1), 9–17.
<https://doi.org/10.1097/00002508-200501000-00002>
- Demir, A. D. (2020). AURA: Altering Self-Perception Through Interactive Light Emitting Textiles. *Proceedings of the 11th Nordic Conference on Human-Computer Interaction: Shaping Experiences, Shaping Society*, 1–3. <https://doi.org/10.1145/3419249.3421234>
- Demir, A. D., Kuusk, K., & Nimkulrat, N. (2022). “Squeaky/Pain”: Articulating the Felt Experience of Pain for Somaesthetic Interactions. *Temes de Disseny*.
- Demir, A. D., Nimkulrat, N., & Kuusk, K. (2022). “Squeaky/Pain”: Cultivating Disturbing Experiences and Perspective Transition for Somaesthetic Interactions. *Diseña*, 20.
- Erdem, D., Yeşilpınar, S., & Şenol, Y. (2018). Design of a Tens Knee Pad with Integrated Textile Electrodes. *Proceedings of the 7th International Technical Textiles Congress*.
- Flink, I. K., Sfyrikou, C., & Persson, B. (2016). Customized CBT via internet for adolescents with pain and emotional distress: A pilot study. *Internet Interventions*, 4, 43–50.
<https://doi.org/10.1016/j.invent.2016.03.002>
- Frances, R., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research. *International Journal of Therapy and Rehabilitation*, 16, 309–314.
<https://doi.org/10.12968/ijtr.2009.16.6.42433>
- Frayling, C. (1993). *Research in Art and Design*. Royal Collage of Art.
- Fyhn, C. (2019, June 3). *A Tangible Understanding of Chronic Pain*. Nordes 2019: Who Cares?
<https://doi.org/10.21606/nordes.2019.002>
- Fyhn, C., & Buur, J. (2020). Chronic Pain Scales in Tangible Materials. *Proceedings of the Fourteenth International Conference on Tangible, Embedded, and Embodied Interaction*, 811–822.
<https://doi.org/10.1145/3374920.3375003>

- Gallagher, S. (1986). Lived Body and Environment. *Research in Phenomenology*, 16(1), 139–170.
<https://doi.org/10.1163/156916486X00103>
- Garrett, R., Popova, K., Núñez-Pacheco, C., Asgeirsdottir, T., Lampinen, A., & Höök, K. (2023). Felt Ethics: Cultivating Ethical Sensibility in Design Practice. *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems*, 1–15.
<https://doi.org/10.1145/3544548.3580875>
- Gastaldo, D., Rivas-Quarneti, N., & Magalhaes, L. (2018). Body-Map Storytelling as a Health Research Methodology: Blurred Lines Creating Clear Pictures. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 19(2), Article 2. <https://doi.org/10.17169/fqs-19.2.2858>
- Gaver, B., Dunne, T., & Pacenti, E. (1999). Design: Cultural probes. *Interactions*, 6(1), 21–29.
<https://doi.org/10.1145/291224.291235>
- Given, L. M. (Ed.). (2008). *The Sage encyclopedia of qualitative research methods*. Sage Publications.
- Goncu Berk, G. (2018). Design of a wearable pain management system with embroidered TENS electrodes. *International Journal of Clothing Science and Technology*, 30(1), 38–48.
<https://doi.org/10.1108/IJCST-04-2017-0047>
- Haines, S. (2015). *Pain is Really Strange*. Singing Dragon.
- Hammal, Z., Berthouze, N., & Walter, S. (2021). Automated Assessment of Pain. *Proceedings of the 2021 International Conference on Multimodal Interaction*, 852–852.
<https://doi.org/10.1145/3462244.3480985>
- Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies*, 17(1), 13–26.
<https://doi.org/10.1080/14725860220137345>
- Höök, K. (2018). *Designing with the Body: Somaesthetic Interaction Design*. MIT Press.
- Höök, K., Caramiaux, B., Erkut, C., Forlizzi, J., Hajinejad, N., Haller, M., Hummels, C., Isbister, K., Jonsson, M., Khut, G., Loke, L., Lottridge, D., Marti, P., Melcer, E., Müller, F., Petersen, M., Schiphorst, T., Segura, E., Ståhl, A., ... Tobiasson, H. (2018). Embracing First-Person

- Perspectives in Soma-Based Design. *Informatics*, 5(1), 8.
<https://doi.org/10.3390/informatics5010008>
- Höök, K., Ståhl, A., Jonsson, M., Mercurio, J., Karlsson, A., & Johnson, E.-C. B. (2015). COVER STORYSomaesthetic design. *Interactions*, 22(4), 26–33. <https://doi.org/10.1145/2770888>
- Hovey, R. B. (2018). The gift of pain with transformative possibilities. *Patient Experience Journal*, 5(1), 11–14. <https://doi.org/10.35680/2372-0247.1248>
- Hovey, R. B., Khayat, V. C., & Feig, E. (2018). Listening to and letting pain speak: Poetic reflections. *British Journal of Pain*, 12(2), 95–103. <https://doi.org/10.1177/2049463717741146>
- Howard, D., & Irani, L. (2019). Ways of Knowing When Research Subjects Care. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–16.
<https://doi.org/10.1145/3290605.3300327>
- Hummels, C., Overbeeke, K. C. J., & Klooster, S. (2007). Move to get moved: A search for methods, tools and knowledge to design for expressive and rich movement-based interaction. *Personal and Ubiquitous Computing*, 11(8), 677–690. <https://doi.org/10.1007/s00779-006-0135-y>
- Ingold, T. (2017). On human correspondence: On human correspondence. *Journal of the Royal Anthropological Institute*, 23(1), 9–27. <https://doi.org/10.1111/1467-9655.12541>
- Kettley, S. (2016). *Designing with smart textiles*. Bloomsbury Publishing Plc.
- Kiger, M. E., & Varpio, L. (2020). Thematic analysis of qualitative data: AMEE Guide No. 131. *Medical Teacher*, 42(8), 846–854. <https://doi.org/10.1080/0142159X.2020.1755030>
- Kodish, B. I. (2004). *Body Awareness in Theory and Practice*. ETC. A Review of General Semantics, 61(3), 353–368. <http://www.jstor.org/stable/42578435>
- Kolcaba, K. Y. (1992). Holistic comfort: Operationalizing the construct as a nurse-sensitive outcome. *Advances in Nursing Science*, 15(1), 1–10. <https://doi.org/10.1097/00012272-199209000-00003>
- Kolcaba, K. Y. (1995). The Art of Comfort Care. *Image: The Journal of Nursing Scholarship*, 27(4), 287–289. <https://doi.org/10.1111/j.1547-5069.1995.tb00889.x>

- Kroes, P. (2022). Design methodology and the nature of technical artefacts. *Elsevier Science Ltd*, 23(3), 287–302.
- Kronsted, C., & Gallagher, S. (2021). Dances and Affordances: The Relationship between Dance Training and Conceptual Problem-Solving. *Journal of Aesthetic Education*, 55(1), 35–55.
<https://doi.org/10.5406/jaesteduc.55.1.0035>
- Kugelmann, R. (2003). Pain as Symptom, Pain as Sign. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 7(1), 29–50.
<https://doi.org/10.1177/1363459303007001305>
- Kuusk, K., Väljamäe, A., & Tajadura-Jiménez, A. (2018). Magic lining: An exploration of smart textiles altering people's self-perception. *Proceedings of the 5th International Conference on Movement and Computing*, 1–6. <https://doi.org/10.1145/3212721.3212893>
- Li, X., Vigil, J. M., Stith, S. S., Brockelman, F., Keeling, K., & Hall, B. (2019). The effectiveness of self-directed medical cannabis treatment for pain. *Complementary Therapies in Medicine*, 46, 123–130. <https://doi.org/10.1016/j.ctim.2019.07.022>
- Lindberg, S., Karlström, P., & Männikkö Barbutiu, S. (2021). Design Ethics in Practice—Points of Departure. *Proceedings of the ACM on Human-Computer Interaction*, 5(CSCW1), 1–19.
<https://doi.org/10.1145/3449204>
- Loke, L., & Robertson, T. (2010). Moving from Experience to Interaction Design. *International Journal of Design*, 4(2).
- Loke, L., & Robertson, T. (2013). Moving and making strange: An embodied approach to movement-based interaction design. *ACM Transactions on Computer-Human Interaction*, 20(1), 1–25.
<https://doi.org/10.1145/2442106.2442113>
- Loke, L., & Schiphorst, T. (2018). The somatic turn in human-computer interaction. *Interactions*, 25(5), 54–5863. <https://doi.org/10.1145/3236675>
- Markussen, T., Bang, A. L., Pedersen, P., & Knutz, E. (2011). *Dynamic Research Sketching- A New Explanatory Tool for Understanding Theory Construction in Design Research*. 1–18.

- McCracken, L. M., Sato, A., & Taylor, G. J. (2013). A Trial of a Brief Group-Based Form of Acceptance and Commitment Therapy (ACT) for Chronic Pain in General Practice: Pilot Outcome and Process Results. *The Journal of Pain*, 14(11), 1398–1406.
<https://doi.org/10.1016/j.jpain.2013.06.011>
- Melzack, R. (1975). The McGill Pain Questionnaire: Major properties and scoring methods. *Pain*.
- Merleau-Ponty, M. (2002). *Phenomenology of perception: An introduction*. Routledge.
- Merritt, M. (2015). Thinking-is-moving: Dance, agency, and a radically enactive mind. *Phenomenology and the Cognitive Sciences*, 14(1), 95–110. <https://doi.org/10.1007/s11097-013-9314-2>
- Morse, J. M., Bottorff, J. L., & Hutchinson, S. (1994). The phenomenology of comfort. *Journal of Advanced Nursing*, 20(1), 189–195. <https://doi.org/10.1046/j.1365-2648.1994.20010189.x>
- Murris, K., & Bozalek, V. (2019). Diffracting diffractive readings of texts as methodology: Some propositions. *Educational Philosophy and Theory*, 51(14), 1504–1517.
<https://doi.org/10.1080/00131857.2019.1570843>
- Neustaedter, C. & Sengers, P. (2012a). Autobiographical Design in HCI Research: Designing and Learning through Use-It-Yourself. *Proceedings of the Designing Interactive Systems Conference (DIS'12)*. <https://doi.org/10.1145/2317956.2318034>
- Neustaedter, C., & Sengers, P. (2012b). Autobiographical design: What you can learn from designing for yourself. *Interactions*, 19(6), 28–33. <https://doi.org/10.1145/2377783.2377791>
- Nilsen, G., & Elstad, I. (2009). Temporal experiences of persistent pain. Patients' narratives from meetings with health care providers. *International Journal of Qualitative Studies on Health and Well-Being*, 4(1), 51–61. <https://doi.org/10.1080/17482620802416129>
- Núñez-Pacheco, C., & Loke, L. (2020). Getting into someone else's *soul*: Communicating embodied experience. *Digital Creativity*, 31(4), 245–258. <https://doi.org/10.1080/14626268.2020.1835987>
- Padfield, D. (2011). 'Representing' the pain of others. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 15(3), 241–257.
<https://doi.org/10.1177/1363459310397974>

- Padfield, D., & Zakrzewska, J. M. (2017). Encountering pain. *The Lancet*, 389(10075), 1177–1178.
[https://doi.org/10.1016/S0140-6736\(17\)30756-0](https://doi.org/10.1016/S0140-6736(17)30756-0)
- Pagé, M. G., Gauvin, L., Sylvestre, M.-P., Nitulescu, R., Dyachenko, A., & Choinière, M. (2022). An Ecological Momentary Assessment Study of Pain Intensity Variability: Ascertaining Extent, Predictors, and Associations With Quality of Life, Interference and Health Care Utilization Among Individuals Living With Chronic Low Back Pain. *The Journal of Pain*, 23(7), 1151–1166.
<https://doi.org/10.1016/j.jpain.2022.01.001>
- Pailes-Friedman, R. (2016). *Smart Textiles for Designers: Inventing the Future of Fabric*. Laurence King Publishing.
- Pauwels, L., & Mannay, D. (2020). *The SAGE Handbook of Visual Research Methods*. SAGE Publications, Inc. <https://doi.org/10.4135/9781526417015>
- Pigeon, W. R., Moynihan, J., Matteson-Rusby, S., Jungquist, C. R., Xia, Y., Tu, X., & Perlis, M. L. (2012). Comparative effectiveness of CBT interventions for co-morbid chronic pain & insomnia: A pilot study. *Behaviour Research and Therapy*, 50(11), 685–689.
<https://doi.org/10.1016/j.brat.2012.07.005>
- Popova, K., Garrett, R., Núñez-Pacheco, C., Lampinen, A., & Höök, K. (2022). Vulnerability as an ethical stance in soma design processes. *CHI Conference on Human Factors in Computing Systems*, 1–13. <https://doi.org/10.1145/3491102.3501994>
- Redström, J. (2017). *Making Design Theory*. The MIT Press.
- Rey, A. E., Michael, G. A., Dondas, C., Thar, M., Garcia-Larrea, L., & Mazza, S. (2017). Pain dilates time perception. *Scientific Reports*, 7(1), 15682. <https://doi.org/10.1038/s41598-017-15982-6>
- Saito, Y. (2022). *Aesthetics of Care: Practice in Everyday Life*. Bloomsbury Publishing Plc.
- Savic, S., & Huang, J. (2014). *Research Through Design: What Does it Mean for a Design Artifact to be Developed in the Scientific Context?* <https://doi.org/10.13140/RG.2.1.4306.6729>
- Scarry, E. (1985). *The Body in Pain: The Making and Unmaking of the World*. Oxford University Press.

- Schiphorst, T. (2009). soft(n): Toward a somaesthetics of touch. *Proceedings of the 27th International Conference Extended Abstracts on Human Factors in Computing Systems - CHI EA '09*, 2427. <https://doi.org/10.1145/1520340.1520345>
- Schneider, S., Junghaenel, D. U., Keefe, F. J., Schwartz, J. E., Stone, A. A., & Broderick, J. E. (2012). Individual differences in the day-to-day variability of pain, fatigue, and well-being in patients with rheumatic disease: Associations with psychological variables. *Pain*, 153(4), 813–822. <https://doi.org/10.1016/j.pain.2012.01.001>
- Schneider, S., Junghaenel, D. U., Ono, M., & Stone, A. A. (2018). Temporal dynamics of pain: An application of regime-switching models to ecological momentary assessments in patients with rheumatic diseases. *Pain*, 159(7), 1346–1358. <https://doi.org/10.1097/j.pain.0000000000001215>
- Schön, D. A. (1984). *The Reflective Practitioner: How Professionals Think in Action* (1st Edition). Basic Books.
- Schouwenberg, L., & Kaethler, M. (Eds.). (2021). *The Autoethnographic Turn in Design*. Valiz, Amsterdam.
- Scott, W., & McCracken, L. M. (2015). Psychological flexibility, acceptance and commitment therapy, and chronic pain. *Current Opinion in Psychology*, 2, 91–96. <https://doi.org/10.1016/j.copsyc.2014.12.013>
- Shapiro, L. (2019). *Embodied Cognition*. Routledge, Taylor & Francis Group.
- Shapiro, L. A. (Ed.). (2014). *The Routledge handbook of embodied cognition* (1 [edition]). Routledge, Taylor & Francis Group.
- Sheets-Johnstone, M. (1979). On Movement and Objects in Motion: The Phenomenology of the Visible in Dance. *Journal of Aesthetic Education*, 13(2), 33. <https://doi.org/10.2307/3331927>
- Sheets-Johnstone, M. (2011). *The primacy of movement* (Expanded 2nd ed). John Benjamins Pub. Co.
- Sheets-Johnstone, M. (2012). From movement to dance. *Phenomenology and the Cognitive Sciences*, 11(1), 39–57. <https://doi.org/10.1007/s11097-011-9200-8>

- Shusterman, R. (1999). Somaesthetics: A Disciplinary Proposal. *The Journal of Aesthetics and Art Criticism*, 16.
- Shusterman, R. (1997). Somaesthetics and the Body/Media Issue. *Body & Society*, 3(3), 33–49.
- Shusterman, R. (2006). Thinking through the Body, Educating for the Humanities: A Plea for Somaesthetics. *Journal of Aesthetic Education*, 40(1), 1–21. <http://www.jstor.org/stable/4140215>
- Shusterman, R. (2008). *Body Consciousness: A Philosophy of Mindfulness and Somaesthetics* (1st ed.). Cambridge University Press.
- Shusterman, R. (2019). Pleasure, Pain, and the Somaesthetics of Illness: A question for everyday aesthetics. In *PATHS FROM THE PHILOSOPHY OF ART TO EVERYDAY AESTHETICS* (pp. 201–214). Finish Society for Aesthetics.
- Singh, A., Piana, S., Pollarolo, D., Volpe, G., Varni, G., Tajadura-Jiménez, A., Williams, A. C., Camurri, A., & Bianchi-Berthouze, N. (2016). *Go-with-the-Flow*: Tracking, Analysis and Sonification of Movement and Breathing to Build Confidence in Activity Despite Chronic Pain. *Human–Computer Interaction*, 31(3–4), 335–383. <https://doi.org/10.1080/07370024.2015.1085310>
- Skop, M. (2016). The art of body mapping: A methodological guide for social work researchers. *Aotearoa New Zealand Social Work*, 28(4), 29–43. <https://doi.org/10.11157/anzswj-vol28iss4id295>
- Sluka, K. A., & Walsh, D. (2003). Transcutaneous electrical nerve stimulation: Basic science mechanisms and clinical effectiveness. *The Journal of Pain*, 4(3), 109–121. <https://doi.org/10.1054/jpai.2003.434>
- Søndergaard, M. L. J., Kilic Afsar, O., Ciolfi Felice, M., Campo Woytuk, N., & Balaam, M. (2020). Designing with Intimate Materials and Movements: Making “Menarche Bits.” *Proceedings of the 2020 ACM Designing Interactive Systems Conference*, 587–600. <https://doi.org/10.1145/3357236.3395592>
- Spyridonis, F., Grønli, T.-M., Paraskevopoulos, I. Th., & Ghinea, G. (2016). A Multi Platform Pain Assessment Tool using Bespoke Gaming Sensors. *Proceedings of the 9th ACM International*

Conference on Pervasive Technologies Related to Assistive Environments, 1–4.

<https://doi.org/10.1145/2910674.2910701>

Ståhl, A., Balaam, M., Ciolfi Felice, M., & Kaklopoulou, I. (2022). An Annotated Soma Design Process of the Pelvic Chair. *Designing Interactive Systems Conference*, 1921–1933.

<https://doi.org/10.1145/3532106.3533469>

Ståhl, A., Balaam, M., Comber, R., Sanches, P., & Höök, K. (2022). Making New Worlds – Transformative Becomings with Soma Design. *CHI Conference on Human Factors in Computing Systems*, 1–17. <https://doi.org/10.1145/3491102.3502018>

Stanton, T. R., & Spence, C. (2020). The Influence of Auditory Cues on Bodily and Movement Perception. *Frontiers in Psychology*, 10, 3001. <https://doi.org/10.3389/fpsyg.2019.03001>

Svanæs, D., & Barkhuus, L. (2020). The Designer’s Body as Resource in Design: Exploring Combinations of Point-of-view and Tense. *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–13. <https://doi.org/10.1145/3313831.3376430>

Tajadura-Jiménez, A., Liu, B., Bianchi-Berthouze, N., & Bevilacqua, F. (2014). Using sound in multi-touch interfaces to change materiality and touch behavior. *Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational*, 199–202. <https://doi.org/10.1145/2639189.2639217>

Tennent, P., Höök, K., Benford, S., Tsaknaki, V., Ståhl, A., Dauden Roquet, C., Windlin, C., Sanches, P., Marshall, J., Li, C., Martinez Avila, J. P., Alfaras, M., Umair, M., & Zhou, F. (2021). Articulating Soma Experiences using Trajectories. *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–16. <https://doi.org/10.1145/3411764.3445482>

Tennent, P., Marshall, J., Tsaknaki, V., Windlin, C., Höök, K., & Alfaras, M. (2020). Soma Design and Sensory Misalignment. *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–12. <https://doi.org/10.1145/3313831.3376812>

Thomas, S. P., & Johnson, M. (2000). A Phenomenologic Study of Chronic Pain. *Western Journal of Nursing Research*, 22(6), 683–705. <https://doi.org/10.1177/019394590002200604>

- Tomico, O., & Wilde, D. (2016a). Embodying Soft Wearables Research. *Proceedings of the TEI '16: Tenth International Conference on Tangible, Embedded, and Embodied Interaction*, 774–777.
<https://doi.org/10.1145/2839462.2854115>
- Tomico, O., & Wilde, D. (2016b). Soft, embodied, situated & connected: Enriching interactions with soft wearables. *mUX: The Journal of Mobile User Experience*, 5(1), 3.
<https://doi.org/10.1186/s13678-016-0006-z>
- Toombs, S. K. (1990). The temporality of illness: Four levels of experience. *Theoretical Medicine*, 11(3), 227–241. <https://doi.org/10.1007/BF00489832>
- Trompetter, H. R., Bohlmeijer, E. T., Veehof, M. M., & Schreurs, K. M. G. (2015). Internet-based guided self-help intervention for chronic pain based on Acceptance and Commitment Therapy: A randomized controlled trial. *Journal of Behavioral Medicine*, 38(1), 66–80.
<https://doi.org/10.1007/s10865-014-9579-0>
- Tsaknaki, V. (2021). The Breathing Wings: An Autobiographical Soma Design Exploration of Touch Qualities through Shape-Change Materials. *Designing Interactive Systems Conference 2021*, 1266–1279. <https://doi.org/10.1145/3461778.3462054>
- Tschaepe, M. (2021). Somaesthetics of Discomfort: Enhancing Awareness and Inquiry. *European Journal of Pragmatism and American Philosophy*, XIII(1). <https://doi.org/10.4000/ejppap.2264>
- Turner, L. (2013). The Evocative Autoethnographic I: The Relational Ethics of Writing About Oneself. Short, N.P., Turner, L. Grant, A. (eds) *Contemporary British Autoethnography*.
https://doi.org/10.1007/978-94-6209-410-9_14
- Umair, M., Alfaras, M., Gamboa, H., & Sas, C. (2019). Experiencing discomfort: Designing for affect from first-person perspective. *Adjunct Proceedings of the 2019 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2019 ACM International Symposium on Wearable Computers*, 1093–1096.
<https://doi.org/10.1145/3341162.3354061>

- Varela, F.J., Rosch, E., Thompson, E. (1993). *The Embodied Mind: Cognitive Science and Human Experience*. The MIT Press
- Vignemont, F. de. (2017). Pain and Touch. *The Monist*, 100(4), 465–477.
<https://doi.org/10.1093/monist/onx022>
- Vilardaga, R., Davies, P. S., Vowles, K. E., & Sullivan, M. D. (2020). Theoretical grounds of Pain Tracker Self Manager: An Acceptance and Commitment Therapy digital intervention for patients with chronic pain. *Journal of Contextual Behavioral Science*, 15, 172–180.
<https://doi.org/10.1016/j.jcbs.2020.01.001>
- Vlaeyen, J. W. S., & Linton, S. J. (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: A state of the art. *Pain*, 85(3), 317–332. [https://doi.org/10.1016/S0304-3959\(99\)00242-0](https://doi.org/10.1016/S0304-3959(99)00242-0)
- Waddington, E. A., Rogers Fuller, R. K., Barloon, R. C. K., Comiskey, G. H., Portz, J. D., Holmquist-Johnson, H., & Schmid, A. A. (2017). Staff perspectives regarding the implementation of a yoga intervention with chronic pain self-management in a clinical setting. *Complementary Therapies in Clinical Practice*, 26, 12–20. <https://doi.org/10.1016/j.ctcp.2016.10.004>
- Wallace, J., McCarthy, J., Wright, P. C., & Olivier, P. (2013). Making design probes work. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 3441–3450.
<https://doi.org/10.1145/2470654.2466473>
- Wilde, D. (2011a). *Extending body and imagination: Moving to move*. 10(1), 31–36.
<https://doi.org/10.1515/ijdhhd.2011.004>
- Wilde, D. (2011b). Extending body and imagination: Moving to move. *International Journal on Disability and Human Development*, 10(1). <https://doi.org/10.1515/ijdhhd.2011.004>
- Wilde, D., Schiphorst, T., & Klooster, S. (2011a). Move to design/design to move: A conversation about designing for the body. *Interactions*, 18(4), 22–27. <https://doi.org/10.1145/1978822.1978828>
- Wilde, D., Schiphorst, T., & Klooster, S. (2011b). Move to design/design to move: A conversation about designing for the body. *Interactions*, 18(4), 22–27. <https://doi.org/10.1145/1978822.1978828>

- Wilde, D., Vallgård, A., & Tomico, O. (2017). Embodied Design Ideation Methods: Analysing the Power of Estrangement. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 5158–5170. <https://doi.org/10.1145/3025453.3025873>
- Wilson, M. (2002). Six views of embodied cognition. *Psychonomic Bulletin & Review*, 9(4), 625–636. <https://doi.org/10.3758/BF03196322>
- Wu, B. (2017). Influence of a Music Therapy Program to Prevent Somatic Symptom Disorder Pain: An Experimental Study. *NeuroQuantology*, 15(3). <https://doi.org/10.14704/nq.2017.15.3.1094>
- Zimmerman, J., Forlizzi, J., & Evenson, S. (2007). Research through design as a method for interaction design research in HCI. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 493–502. <https://doi.org/10.1145/1240624.1240704>