UNIVERZA NA PRIMORSKEM
FAKULTETA ZA MATEMATIKO, NARAVOSLOVJE IN INFORMACIJSKE TEHNOLOGIJE

MASTER'S THESIS
(MAGISTRSKO DELO)

EXPERIENTIAL COMPONENTS OF FIBROMYALGIA: PHENOMENOLOGICAL UNDERSTANDING AND AWARENESS OF THE EXPERIENCE OF SYMPTOMS

(DOŽIVLJAJSKE KOMPONENTE FIBROMIALGIJE: FENOMENOLOŠKO RAZUMEVANJE TER OZAVEŠČANJE IZKUŠNJE SIMPTOMATIKE)

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(Doživljajske komponente fibromialgije: fenomenološko razumevanje ter ozaveščanje izkušnje simptomatike)

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Izvleček:

Sindrom fibromialgije je kronično stanje, za katero je značilna razširjena mišično-skeletna bolečina in številni simptomi, vključno z utrujenostjo, motnjami spanja, kognitivno disfunkcijo in psihološkimi stiskami. Simptomi vključujejo razpršeno skeletno mišično bolečino vratu, ramenskega in medeničnega obroča, zgornjega dela prsnega koša, komolcev in kolen, ki izvira v globje ležečih mehkih tkivih (mišice, tetive, vezi). FMS pomembno vpliva na kakovost življenja in na odnos bolnika s svojim telesom; bolniki poročajo o spremembi telesne podobe. Zdravljenje FMS zaradi nejasne etiologije in patogeneze ostaja pomemben izziv in trenutno ni znanega zdravila. Namen magistrskega dela je doprinesti k poglobljenemu razumevanju doživljanja bolečine in drugih simptomov fibromialgije kot kroničnega bolečinskega sindroma, ter razumevanje procesa soočanja s sindromom fibromialgije. Z dobljenimi rezultati smo želeli prispevati k razumevanju učinka ozaveščenosti lastnega telesnega stanja, razvoja in sprejemanja bolezni pri bolnikih s sindromom fibromialgije. Poskusna teorija je bila uporabljena kot teoretični okvir in analitična metoda. Analizirali smo 21 mikrofenomenoloških intervjujev, šest pol-strukturiranih anamnestičnih intervjujev in 21 slik preslikave telesa na vzorcu šestih žensk. Bolečina in zavedanje telesa sta opredeljeni kot subjektivni izkušnji. Življenje s kronično bolečino bistveno vpliva na spremenjeno dojemanje telesa. Udeleženci opisujejo težko in utrujeno telo v trenutkih močne bolečine, kjer se ustvari pregrada med telesom, okoljem, odnosi in čustvenim stanjem. V trenutkih, ko je simptomatika manj prisotna, telo dojemajo lahkotno ter kot vir užitka. Specifičnost fenomenološkega pristopa nam je omogočila zbrati in analizirati opise telesnih izkušenj bolnikov s fibromialgijo. Jasnost in bogata raba jezika pripomore k bolj obsežnim in raznolikim podatkom, ki nudijo globlje vpoglede v znanstvena vprašanja. Tako lahko izpostavimo, da je fenomenologija ustrezna metoda raziskovanja doživljanja za FMS.

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Abstract:

Fibromyalgia syndrome is a debilitating syndrome characterized as chronic widespread musculoskeletal pain and fatigue. FMS has a significant influence on quality of life and the patient's relationship with their body; patients report an alteration of one's body image. The treatment of FMS remains, because of its unclear etiology and pathogenesis, a significant challenge and there is currently no known cure. In the master's thesis, we were interested in understanding the in-depth experience of pain and other FM symptoms as a chronic pain syndrome. Moreover, we were interested in analyzing body awareness of one's own physical condition, and the development and acceptance of the disease. The grounded theory was used as the theoretical framework and analytical method. We examined 21 micro-phenomenological interviews, six semi-structured anamnestic interviews and 21 body-maps in six women. Pain and body awareness are defined as subjective experiences. Living with chronic pain is affected by a changed perception of the body. Participants describe a heavy and tired body in moments of intense pain, where a barrier is created between the body, environment, relationships, and emotional state. In experiencing improvement in symptoms, the body is perceived as lightness and a source of pleasure. The specificity of the phenomenological approach has enabled us to gather and analyze descriptions of the bodily experience of patients suffering from FM. Clarity and rich use of language contribute to more comprehensive and diverse data that offer deeper insights into scientific issues. Thus, we can emphasis that phenomenology is an appropriate method of researching experience for FMS.

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LIST OF ABBREVIATIONS

ACR	American Rheumatological Association
CNS	Central nervous system
DLX	Duloxetine
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
EULAR	The original European League Against Rheumatism
FM	Fibromyalgia
FMS	Fibromyalgia Syndrome
IASP	The International Association for the Study of Pain
ICD 10	The International Classification of Diseases
MAIA	Multidimensional Assessment of Interoceptive Awareness
MLN	Milnacipran
PGB	Pregabalin
SNRI	Serotonin-Noradrenalin Reuptake Inhibitors
URI	University Rehabilitation Institute Soča

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1 INTRODUCTION

Pain changes and affects the quality of life more than any other health related issue and is one of the tools of protecting the body. Pain, especially chronic pain is an area that is still poorly understood. The most significant emphasis is on the study of physiology, although the field is much more complex. Pain is associated with discomfort and intense instances of unpleasant conscious experience. Evolutionary it is regarded as an essential driving force of natural selection, since perceiving pain is crucial to survival. Pain protects us by triggering an automatic withdrawal from potentially dangerous stimuli before we can suffer further injuries. Or it tells us that an injury will soon occur, when to seek medical help, and teaches us what behaviours should be avoided in the future. It promotes positive behaviour. In some rare cases, a condition studied has been associated with insensitivity to pain, which is a hazardous condition; people can not feel pain.

However, if pain occurs under the wrong circumstances, such as the absence of physical injuries, or the duration of pain lasts even when the damaged tissue has already recovered, it represents one of the most common and critical medical issues. We decided to investigate chronic pain in more detail, focusing specifically on fibromyalgia syndrome, which significantly impacts physical and mental well-being. People face burdened circumstances without a clear awareness of the actual events in the body. A lack of understanding of the disease and unclear guidance from professionals makes it challenging to design clear and effective therapies. Qualitative aspects of the patient's perception of life with fibromyalgia are rarely examined. In the theoretical part, more is written about the problem of chronic pain and fibromyalgia syndrome from both a biological and a psychological/phenomenological point of view.

Furthermore, we wanted to delve deeper into understanding the experience of FM and study this; therefore, the research is based on the foundations of the phenomenological method of analysis. With the findings, we wanted to add new insights to the understanding of patients' experience with FMS and the factors that have a significant impact on the experience itself. The qualitative research results are presented and supported by examples, followed by interpretation and connection with the known theoretical frameworks. Based on the collected data, we designed the grounded theories, which are presented and are the foundations of the research of the master thesis.

1.1 CHRONIC PAIN

Pain is a salient personal experience that is modulated on a cognitive level and affects attention, anticipation, emotional process and memory of the past painful experience.
In 2020, IASP presented a revised definition of pain. Pain is defined as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020, pg. 2). Additionally, it is developed in an extension of the six main vital points. Pain is a personal experience influenced by biological, psychological, and social factors, so inferences are not possible solely from neural sensory activities. Nociceptin and pain are not the same phenomena. Through life, we learn the concept of pain. Every painful experience of an individual must be respected. Verbal expression of pain is only one way of describing pain; the inability of verbal communication does not exclude that a human or non-human animal experiences pain. Despite the fact that pain has the role of adaptation, it can also have detrimental effects on psychological well-being and functioning (Raja et al., 2020).

While IASP defines pain as a subjective experience, it is not a constant practice among healthcare professionals. Medical specialists often search for objective pain measures and seek technological resolutions or fixes for persistent pain. Unfortunately, these approaches do not have a substantial impact on the burdens of persistent nonspecific pain (Stilwell and Harman, 2019). Pain is generally divided into three classes: nociceptive pain, inflammatory pain, and pathological pain. Non-receptive pain represents the sensation of detecting and perceiving harmful stimuli that could damage the tissue and thus contributes protection. Inflammatory pain is associated with tissue damage. Stimulates repair through hypersensitivity to pain until healing occurs. Pathological pain is a medical condition caused by a malfunction of the nervous system or its abnormal functioning (Woolf, 2010). The time perspective of the duration of the pain process is the most obvious way to differentiate in pain classification. Furthermore, it is a crucial factor in understanding the neurophysiology of pain. Acute pain is limited to pain less than three to six months. When the pain-causing condition resolves, the pain stops. It is helpful and has a protective function. It warns of danger, limits the use of damaged body parts, and warns of the departure of pathology when the restrictive condition is resolved (Thienhaus and Eliot Cole, 2001). Pain is classified as chronic when it lasts longer than three to six months or it extends beyond the expected period of healing. Accompanying cognitive changes in patients with chronic pain often include excessively focused attention to pain, pain-related information, and a reduced amount of residual sensory inputs (Martínez et al., 2018). Understanding this complex phenomenon demonstrates one of the oldest and most significant challenges in medical history. Pain has a meaningful role in medical action as a biological protective tool and automatic physical adjustment. However, the discovery of abnormal pains, like chronic pain, is the phenomenon that starts the traditional understanding of pain as a symptom of disease to weaken. When pain persists past the standard healing time or recurs for months or years, its function as a protective toll is lost. Furthermore, it becomes a pathological condition that severely impacts life quality. It includes a loss of physical or/ and emotional function, activity levels, and economic consequences as a result from health care expenses and the potential decrease in financial income (Raffaeli and Arnaudo, 2017). Chronic pain is one of the most common complaints in the medical field. Estimations by The International Association for the Study of Pain (IASP) shows that chronic pain, including musculoskeletal and joint pain, neck and back pain, trauma and post-chirurgical pain, cancer pain, and chronic headache, afflicts approximately 20 % of the adult population all over the world (Queiroz, 2013).

In the last three decades, much evidence showed that chronic pain is not just a physical phenomenon, defined by the biomedical model, but is instead explained by the biopsychosocial model. The biopsychosocial model interpretation is based on the interaction of biological, psychological, and social components that influence the experience, coping strategies, and treatment options for the pain (Bevers et al., 2016). The biopsychosocial model was an acknowledgement to the reductionist use of the biomedical model in clinical practice, as the mentioned approach, does not explain complex health conditions, like non-specific chronic pain. Biopsychosocial model should provide a better understanding of the psychosocial and sociocultural aspects of pain, emphasising biology. With the idea of the model, crucial advances have been made in the science of pain, such as understanding neuroplasticity, central hypersensitivity, and a better knowledge of the purpose of anxiety, depression, anger, fear, and catastrophe in the pain experience. The biopsychosocial model includes certain limitations, such as the artificial setting of biological, psychological, and social boundaries. Due to certain conditions, it retains dualistic and reductionist beliefs in its theoretical foundation. Consequently, we will mention also the 5E model, that is grounded in phenomenology and cognitive science and to which we will refer in the discussion. Model 5E conceptualizes pain as embodied, embedded, established, emotional, and extended. It apprehends pain as a process of making sense through a living body, inseparable from the world we shape and shape ourselves (Stilwell and Harman, 2019).

Many genes are associated with pain sensitivity, and there is incomplete overlap between these genes and chronic pain conditions. Chronic pain may be related to several overlapping pathways between pain and psychological responses to pain. Two main pathways of neurotransmitters have been repeatedly associated with musculoskeletal pain. The first is the adrenergic pathway, and the second is the serotonin pathway. These genetic pathways are associated with endophenotypes, or intermediate measurable phenotypes present in patients with chronic pain. They include autonomic dysregulation, altered pain processing, modulation and sleep dysfunction in the adrenergic pathway. In addition, personality and affective traits such as somatic awareness, depression, and anxiety are associated with genetic changes in the serotonin pathway that is furthermore linked to chronic pain (Crofford, 2015). Chronic pain is associated with a changed body perception that cannot be understood by the peripheral deficit. As it seems, chronic pain states are best explained by peripheral deficits and the involvement of cortical representations (Trojan et al., 2014). Various studies demonstrate that patients with chronic pain have brain changes in the cognitive and emotional modulation of pain. This complex interaction may (partly) explain why patients with long-term chronic pain develop anxiety and depression and why those with cognitive distortions and psychological distress are at greater risk for chronic pain and central pain intensification (Crofford, 2015).

Chronic widespread pain is present in approximately 10% of the population; meanwhile, chronic regional pain is present in 20% to 25% of the general population. The symptoms often vary over time, with one or the other dominant at a given point in time. It also clusters with other somatic symptoms, including fatigue, unrefreshing sleep, dyscognition, and mood disturbances. Other clinical syndromes, such as chronic fatigue syndrome/myalgic encephalomyelitis, have musculoskeletal pain as part of the diagnostic features. This leads to the frequent presence of multiple diagnoses and multiple providers interacting with a given patient, potentially leading to numerous testing that may increase anxiety and numerous drug treatments that may interact or cause adverse effects (Crofford, 2015).

1.2 FIBROMYALGIA

Fibromyalgia syndrome is one of the leading types of widespread chronic pain (Queiroz, 2013). It is mainly characterized by chronic generalized, widespread pain at several points along the body (Logar, 2011), without a well-defined underlying organic disease or injury (Bellato et al., 2012). Clinical diagnosis is exclusionary and follows the criteria of the ACR, which was developed in 1990, and revisioned 20 years later in 2010 (Arnold et al., 2008). FMS includes a range of disease states that occur because of inflammatory or degenerative soft tissue changes. Scattered skeletal muscle pain, which is dull, burning (Logar, 2011), aching or sore (Cohen, 2017), extends from the neck, shoulder, pelvic girdle, upper chest, elbows, and knees. The pain results from deeper soft tissues (muscles, tendons, and ligaments) whose location cannot be determined precisely (Logar, 2011). Pain is a subjective experience. Valenzuela-Moguillansky (2013) described three main types of pain observed and identified in fibromyalgia (FM) patients concerning localization, quality, intensity, and frequency. The first type of pain is constant but not intense, mainly in the back, shoulders, and neck. The FM patients described it as heaviness and tiredness. The second type of pain is more intense and local. The pain can insist for weeks or months, mostly in the hips and legs. The last and third type of pain is a very intense but temporary pain described as stabbing. The etiology remains unknown, but recent advances have helped explain some of the secrets of the disease. Researches highlight some abnormalities in biochemical, metabolic, and immunoregulatory activity. Currently, FMS management is complex because it has several etiological factors and psychological predispositions. The key to successful treatment is using a patient-centred approach (Jahan et al., 2012).

In the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), FMS is classified as a “somatic symptom disorder” (Wolfe et al., 2014). In the International Classification of Diseases (ICD-10), it is classified under the XIII Diseases of the musculoskeletal system and connective tissue, M79; Other soft tissue disorders, not elsewhere classified, code M79.7. (ICD, 2021).

1.2.1 History

The first description of the "pain syndrome" in the absence of any organic disease was introduced in 1904 by Gowers and was named "fibrositis" (Bellato et al., 2012). The clinical picture was described as an "inflammatory disease" (Lakomek et al., 2007). The name lasted for several years until the mid-1970s, when they discovered the central nervous system's involvement and identified regions on the body of extreme tenderness. The symptoms were given the name we are familiar with now, "fibromyalgia" (Bellato et al., 2012) and included both a musculoskeletal disorder as well as a functional clinical picture (Lakomek et al., 2007).

1.2.2 Aetiology and Pathogenesis

The aetiology and pathogenesis of the FMS are still not fully elucidated (Bellato et al., 2012). Fibromyalgia is a medically unexplained functional somatic symptom that cannot be explained by organic dysfunctions (Courtois et al., 2015). Over the years, the understanding of FMS as a mainly peripheral musculoskeletal pathology has shifted to a state of centralized pain with a chronically extended pain spectrum (Cohen, 2017).

The definition, classification, and diagnosis of FM differs between the individual medical societies as well as between doctors, psychologists, and those affected (Eich et al., 2012). The various symptoms and associated diseases with FMS represent a challenging diagnostic process and treatment (Cohen, 2017). FMS can develop spontaneously but is probably the result of a stereotypical, maladaptive, biological response of the body on the chronic or cumulative physical and/or psychological stress in genetically predisposed individuals (Kwiatek, 2017).

Due to its unknown aetiology, many theories and hypotheses were suggested explaining the syndrome's pathophysiology (Nihalani et al., 2006). There is no known defining factor responsible for the onset of the syndrome (Bellato et al., 2012). Few factors are associated (functional changes associated with or resulting from the disease), but the relationship is unclear. The functional modifications include altered central nervous system dysfunction (changes in sensory processing, reduced reactivity of the hypothalamus-pituitary-adrenal axis to stress, increased pro-inflammatory and reduced anti-inflammatory cytokine profiles) (Derry et al., 2016), altered neurotransmitter function (Bellato et al., 2012), dysregulation of pain pathways (Arnold et al., 2008), hormones and immune system (Bellato et al., 2012).

FMS's characteristic of increased pain and lowered pain thresholds (increased sensitivity to light touch or embrace) is considered multifactorial. They may include adjusted chemistry in the hypothalamic-pituitary axis, abnormal corticotropin-releasing factor in the cerebrospinal fluid, abnormal N-methyl d-aspartate, and finally, an emotional affective acknowledgement of pain (Wright et al., 2011). Some contemporary trigger factors e.g. infections (borreliosis, a herpes virus infection 6, rubella virus or parvovirus B19, hepatitis virus C), prolonged excessive environmental noise, and prolonged psychological stress (Logar, 2011) may contribute to functional changes in predisposed individuals (Derry et al., 2016). The symptoms of the syndrome are complex and heterogeneous (Mendonça Araújo and DeSantana, 2019). Currently, there is no definitive cure available, and the prognosis is uncertain. The therapies are primarily focused on managing the symptoms (Wuytack and Miller, 2011). The condition often overlaps with other diseases or syndromes (Vincent et al., 2013) and presents limitations and challenges in the diagnostic and treatment process (Mendonça Araújo and DeSantana, 2019).

1.2.3 The central nervous system

Some rheumatologists, neurologists, and pain therapists, and many patients view FMS as a specific clinical picture with associated muscle and connective tissue disease factors or typical changes in central nerve function (Häuser et al., 2009).

The central nervous system hypersensitivity is considered to be the primary mechanism by which the organism responds to stimulation mediated by CNS signaling with a more significant response. Central hypersensitivity develops as spontaneous nervous activity, increased receptive fields, and increased stimuli transmitted by primary afferent fibers (Bellato et al., 2012). Abnormal sensory impulses cause the pain component of fibromyalgia, usually referred to as central sensitization. This phenomenon is characterized by persistent hyperexcitability in dorsal horn neurons, which continues long after the original sensitizing input has declined. The pain pathway from the spinal cord to the brain is accentuated by a descending pain pathway arising in the brainstem (Benett and Nelson, 2006). Activated glial cells play a crucial role in maintenance. They affect the release of the cytokine IL-1, IL-6, substance P, nitric oxide, and excitable amino acids and fractal acids, which causes excessive excitation of the neurons of the posterior horns of the spinal cord (Logar, 2011). When central overexcitation occurs, even a small number or intensity of pain stimuli is sufficient to maintain chronic pain. The timing of subsequent pain stimuli with pain intensification is called the wind-up phenomenon (Logar, 2011). After a painful stimulus, future stimuli of the same intensity are perceived as more potent. The phenomenon, which is an expression of neuroplasticity, occurs in all people, with the difference that it is excessive in patients with FMS (Bellato et al., 2012). The pain generation system of the central neural system is decayed, and therefore the response of the brain to pain is different in FMS patients than in healthy people (Semiz et al., 2016). Varied studies appear to confirm hyperactivation of the sympathetic nervous system persistently hyperactive to stress. High serum levels of neuropeptide Y, typically secreted accompanying norepinephrine, indicate this dysautonomic state of the system. With these findings, we can explain some clinical symptoms, such as intestinal irritability and fatigue (Bellato et al., 2012).

Serotonin is an essential amino acid that reduces pain by capturing the release of substance P and irritant amino acids in the spinal cord. If the central nervous system level is too low, it reduces the activity of progeny inhibitory neurons in the spinal cord. All these changes cause a lowering of the pain threshold. Recent research and functional neuroimaging confirm that they are excessively irritated in patients with fibromyalgia pain pathways in the spinal cord's posterior horns (Logar, 2011). Serotonin plays a meaningful role in regulating sleep and mood, explaining the link between fibromyalgia and sleep and mental disorders (Bellato et al., 2012).

Pain-conducting myelinated A-delta fibers (initial pain, conduction velocity 10 m / s) and unmyelinated C fibers (subsequent pain, playback speed 1.6 m / s) switch to specific nociceptive projections neurons translating a more comprehensive range of arrest stimuli. Repeated stimulation of C fibers through increasing the frequency of electrical impulses from neurons posterior horns of the spinal cord is in FM patients stronger than in healthy people. We are talking about time summing subsequent pain stimuli with reinforcement pain (cheering phenomenon) and about the central phenomenon of excessive irritability with increased spontaneous activity neurons, which is clinically manifested as hyperalgesia in allodynia (Logar, 2011).

Furthermore, evidence demonstrates that changes occur in the morphology of the brain. Volume changes in grey matter, amygdala, cingulofrontal, postcentral gyri, anterior cingulate, hippocampi, striatal, superior frontal, and insular are perceived in FMS patients that are suffering from chronic pain as well as a reduction in cortical thickness and overall cortical volume. Neuroplasticity of the brain may explain the changes from experiencing acute pain to chronic pain development (Cohen, 2017).

1.2.4 Symptoms of Fibromyalgia

Fibromyalgia syndrome is generally associated with persistent widespread pain and abnormal pain sensitivity (Nihalani et al., 2006), such as hyperalgesia (pain that is increased by regular painful stimulus) or allodynia (non – pain stimulus induce pain) (Cassisi et al., 2014). While the primary characteristics of FMS are independent of psychological status, it is proposed that psychological factors may affect the severity of pain. As in most chronic pain diagnoses, the FMS clinical manifestations are more complex than the body pain alone (Shuster et al., 2009). The syndrom is often accompanied by somatic symptoms, mood disorders, like depression and anxiety, cognitive dysfunction/ reduction of cognitive performance, sleep disturbance, insomnia and chronic fatigue syndrome (Bellato et al., 2012). They are often accompanied by difficulties with working memory processes and/ or in their attentional and executive domains and processing speed (Gelonch et al., 2018). These symptoms contribute to the complexity of achieving adequate symptom management in FMS (Shuster et al., 2009). With the development of the syndrome and the onset of symptoms, patients report a decrease in the functional ability to cope with everyday circumstances, a gradual decline in quality of life (Mendonça Araújo and DeSantana, 2019), work disability, and uncertainty (Sharon, 2006). Common and shared physical features of FMS patients are restless legs, joint morning stiffness, a sensation of tissue swelling (Cohen, 2017), and decreased aerobic capacity. Often the symptoms worsen with cold, stress, too much physical activity, and improve with warmth, rest, and adequate level of physical exercise (Logar, 2011).

1.2.5 Epidemiology of Fibromyalgia

Fibromyalgia syndrome affects millions of people worldwide. The numbers of prevalence vary widely, between 0.2 and 6.6% of the world's Western society (Verbunt et al., 2008). Different reviews show a slightly different FMS epidemiology state (Häuser, 2018). A review that analysed 26 studies of FMS prevalence worldwide showed a 2,7% prevalence in the general population. A crucial study, which provides comprehensive data on the prevalence of FM using diagnostic criteria of the ACR 2010 criterion, states that the prevalence of the diagnosis of the syndrome in the general population is 5.4% (Fayaz et al., 2016). Moreover, it was recognised to be more common in women (Queiroz, 2013) and it increases with age (Shuster et al., 2009). The vulnerable group includes patients over the age of 50, people with a low level of education, low socioeconomic status, living in rural areas.

The prevalence of the syndrome depends on the definition of the disease used to determine a particular pathological condition (Häuser, 2018). The ACR 2010 diagnostic criteria eliminated the review of tendering points and allowed their use in epidemiological and clinical studies without the need for a medical examination (Wolfe et al., 2011). The relation between gender and FMS is very controversial (Wolfe et al., 2018), but the current results show that it occurs seven times more frequently in women than in men (Nihalani et al., 2006), with a female-male ratio of 8-10: l. However, in epidemiological studies using the 2011 criteria, without tender points, the female-male ratio is 1 -2: 1. Gender differences between clinical and epidemiological studies can be explained with the following arguments. The ACR 1990 classification criterion is used for diagnosis. There is a bias towards a faster diagnosis of the female sex, as a lower pain threshold may explain advertised points in women than in men. In Western countries, women are more likely to consult health professionals in psychological or somatic problems (Häuser, 2018). Studies on the prevalence of the disease are important to understand better the range of the problem in the general population and therefore help provide appropriate assistance to patients with FM (Queiroz, 2013).

1.2.6 Clinical diagnosis

The absence of objective markers or reliable and valid clinical measures for FMS diagnosis represents a significant problem in clinical practice (Bellato et al., 2012) that creates confusion for caregivers and those who are affected. Consequently, patients may evolve a feeling of lack of recognition, a sense of meaninglessness, and stigmatization (Courtois et al., 2015). Since the symptoms are often vague, heterogeneous, and complex, the disease diagnosis is difficult to settle and often takes several years and different specialist appointments (Bellato et al., 2012). The complexity of the disease results in a stigmatized health identity in patients. The stigma consisted of questioning the integrity, morality, and accuracy of patient symptom descriptions and psychologizing symptoms (Åsbring and Närvänen, 2002). From the beginning of obtaining a diagnosis, it threatens the patient’s identity, mainly due to the diagnosis's legitimacy and frequent doubts by medical staff. Individuals' responses and the management of their disease are deeply socially embedded and vary according to their health identity and social statuses such as socio-economic status, age, gender, nationality, religion, and disability (Lempp et al., 2009). As a result, patients resort to various strategies that include withdrawal and accession strategies, depending on individual circumstances and goals (Åsbring and Närvänen, 2002). Åsbring and Närvänen (2002) investigated stigmatization associated with fibromyalgia and showed findings that suggest more present stigmatization in the post-diagnosis period. There are several doubts about the symptoms' reality during this period due to the "invisibility" of the disease. Patients report that they have been unfairly accused of lying about their plight, thereby negatively affecting their credibility (Åsbring and Närvänen, 2002).

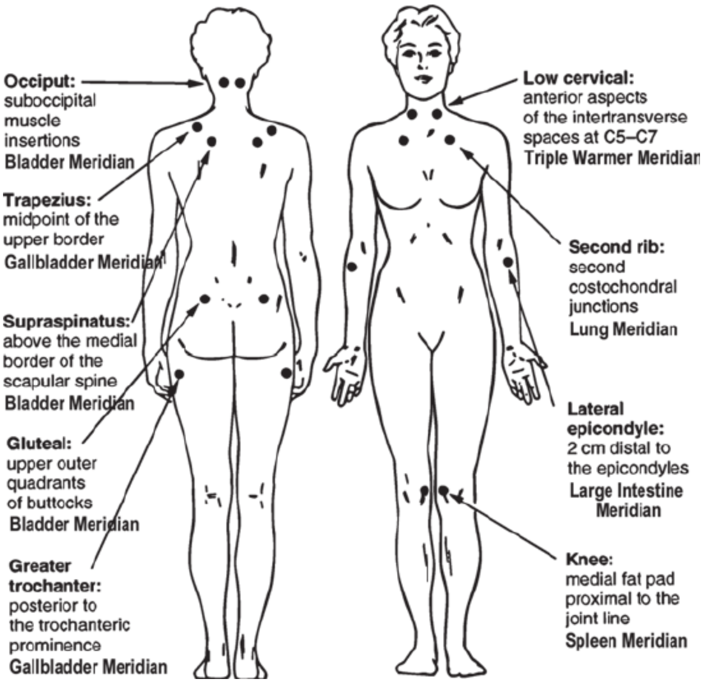
The first step in the diagnostic process is the patient's medical history, which mainly includes studying a typical symptomatic complex (Lakomek et al., 2007). FMS's primary symptoms are chronic pain in several parts of the body, disturbed sleep / not restful sleep, physical / mental fatigue, or/and an increased tendency to exhaustion. Almost all patients report further physical and emotional complaints (Häuser, 2016). Often the diagnosis is made as a differential diagnosis (Lakomek et al., 2007), as the exclusion of other possible diseases (Cohen, 2017), like neurological and orthopaedic diseases that could adequately explain symptoms (Häuser, 2016). Differential diagnosis represents an essential and necessary part of the clinical diagnosis process (Lakomek et al., 2007).

Over the decades, experts have sought to develop diagnostically uniform criteria for the condition we recognize today as FMS. In 1990, the American Academy of Rheumatology (ACR) developed a set of diagnostic criteria (Kumbhare et al., 2017) that have been the main criteria for the clinical diagnosis of FMS. Two decades later, in 2010, the criteria were supplemented (Logar, 2011).

The first form of diagnostic criteria in 1990 included chronic diffuse pain throughout the body, localized in the left and right halves of the body, upper and lower body, as well as axial skeleton pain lasting more than three months. Furthermore, the criterion includes at least eleven pain points due to pressure, out of a total of eighteen. When checking these gentle points, the pressure has to be 4 kg each. Just one year after publication, Wolfe proposed a change in the application of the criteria (Lakomek et al., 2007). In the establishment of the diagnostic criteria, there was too much focus just on pain and excluded other associated symptoms. As a result, the diagnostic criteria were somewhat deficient for use in clinical practice (Arnold et al., 2019).

Figure 1

ACR fibromyalgia tender point map (Leskowitz, 2008)



The suggested criteria that Wolfe required to include was chronic fatigue syndrome, irritable colon syndrome, and psychosomatic disorders like headache, "racing heart," "heart stumbling," as well as sleep abnormalities and anxiety (Lakomek et al., 2007). Almost twenty years later, the diagnostic criteria were redefined and shifted from a predominantly chronic pain disorder to a multi-symptom disorder (Arnold et al., 2019). In 2010, the ACR developed a new version of the diagnostic criteria based solely on the use of two criteria, namely the Widespread Pain Index and the Symptom Severity Scale. The pain prevalence index (WPI) contains a list of 19 painful areas (range 0-19). Patients report the presence and intensity of pain for each point separately. The symptom severity scale (SS) includes two parts, the SS2a part (four-point scale) assesses the severity of fatigue, sleeplessness, and cognitive symptoms of the disease. Part SS2b consists of a checklist of 41 symptoms. Patients report information on the presence or absence of these symptoms (Galvez-Sanchez and Reyes Del Paso, 2020). Three conditions must be met according to revised diagnostic criteria: Widespread pain index (WPI) ≥ 7 and Symptom severity (SS) scale score ≥ 5 or WPI 3-6 and SS scale score ≥ 9, the symptoms have to be present at least three months with a similar intensity and the patient has excluded differential disorders which would otherwise explain the pain (Courtois et al., 2015). The ACR 1990 classification criteria and the modified ACR 2010 criteria can be used for a clinical diagnosis of FMS (Derry et al., 2016). The ACR 1990 criteria and the 2010 revision reflect a conceptual change in the way we think about FMS or the classification from pain syndrome to multi-symptom syndrome

(Jones et al., 2015). In 2011 a new modified ACR 2010 criteria was developed and published. It allows the use in epidemiological and clinical studies without the requirement of a clinical examination. Epidemiological studies are necessary to better understand the range of the problem in general populations or specific settings to calculate the appropriate resources to provide FM sufferers' adequate assistance (Queiroz, 2013).

When the symptoms meet the criteria of FMS, and the diagnosis is made, it is necessary and meaningful to explicitly communicate it to the patient. Clinical experience shows that most affected are relieved to learn that their complaints are known to one and correspond to well-researched clinical pictures (Eich et al., 2012). The label "fibromyalgia syndrome" can enable many sufferers to draw attention from the search for the cause of their complaints and get start to actively seek solutions and strategies to cope with the disease (Häuser, 2016). The results of a study made in Canada are showing a greater patient satisfaction with their mental state and reduction in symptom incidence 18 months after the clinical diagnosis (Eich et al., 2012). Important information to be communicated after the initial diagnosis is that symptoms do not necessary lead to disability and do not shorten the life expectancy; it is mostly a chronic disease, a "cure" (complete freedom from symptoms) is usually not possible. Aim of therapy is improvement or maintenance of the quality of life (functionality in everyday life, symptom reduction) (Häuser, 2016). The education about the disease should be explained on a biopsychosocial disease model, which emphasizes the psychophysiological relationship (stress and the circular model) (Eich et al., 2012).
The information they receive at the time of diagnosis affects the progression of symptoms, the perception of the severity of symptoms, and treatment choice. Lack of diagnosis information can lead to a lack of confidence in professional medical staff's recommendations in patients (Taylor et al., 2016).

1.3 CLINICAL TREATMENT

FMS is known to be challenging to treat efficiently; only a minority of individuals are undergoing a clinically relevant advantage from interventions (Moore, et al., 2014). The lack of unifying pathophysiology and non-diagnostic tests is mirrored in no definitive treatment for FMS (Kia and Choy, 2017); as mentioned, no cure is currently available (Wuytack and Miller, 2011) nor any consent on how to accurately manage the disease (Lempp et al., 2009). The existing treatments are often contradictory and inefficient (Kia un Choy, 2017) as well as very challenging for both patient and health care practitioners (Wuytack and Miller, 2011). It seems that a multidimensional approach based on the biopsychosocial model, including pharmacological and non-pharmacological treatments is currently most efficient for managing the symptoms (Kwiatek, 2017). It incorporates symptom management through pharmacological medication, cognitive-behavioral therapy, and physical activity (Seto et al., 2019). The first and significant step in the treatment of FMS is to educate the patients about the disease's nature. The treatments are successful only if the patients take an active role in the treatment itself as an equal member of the professional therapeutic session (Logar, 2011). Managing and adapting to a chronic disease such as FMS requires creating a meaning of the disease. The new information affects the patient’s identity and self-efficacy, representing an essential cognitive factor for managing symptoms such as pain. Belief in self-efficacy helps to explain many behaviours and the ability to cope with them (Taylor et al., 2016).

1.3.1 Pharmacological treatment

Pharmacological treatment has a supportive role in managing symptoms (Kwiatek, 2017). Medications work best when used for symptomatic relief, so patients can engage in treatment with non-pharmacological methods that allow long-term disease management strategies (Ormseth et al., 2010).

For FMS's pharmacological treatment, the Federal Food and Drug Administration (FDA) has approved three drugs: Lyrica (pregabalin), Duloxetine, and Milnacipran. When the pharmacological treatment does not show any improvement or noticeable side effects, treatment should be discontinued (Kia and Choy, 2017).

1.3.1.1 Anticonvulsants

Pregabalin (PGB) is recognized under the drug classification *gabapentinoids* and was developed as anti-seizure medications or anticonvulsant (Goodman and Brett, 2019). The active substance pregabalin is an analogue of gamma – aminobutyric acid (Boomershine, 2010). The mechanism of action works by binding to an auxiliary subunit (α2-δ protein) of voltage-gated calcium channels (Derry et al., 2016). It works by decreasing excitatory neurotransmitters in the central nervous system (Boomershine, 2010). It is used to treat neuropathic pain, epilepsy, and generalized anxiety disorder. The pharmacological activity confers analgesics, antiepileptic, and anxiolytic effects (Derry et al., 2016).

Lyrica (pregabalin) was the first drug approved by the FDA for treating FMS (Abalin and Buskila, 2010) in 2007 (Goodman and Brett, 2019). Side effects limit their use, and not all patients experience improvement (Abalin and Buskila, 2010). In a randomized, double-blind, placebo-controlled monotherapy trial, pregabalin's effectiveness was studied and demonstrated as statistically significant at different doses compared with placebo (Arnold et al., 2008).

Cochrane’s report, which included nine review articles examining the effectiveness of pregabalin for treating FMS, reported that patients who were actively receiving treatment were more likely to have a 30% reduction in pain compared with 9.95% placebo. Meanwhile, it has been found to have little effect on fatigue and sleep and does not affect disability (Macfarlane et al., 2017).

Gabapentin (GBP) is another antiepileptic medication, sometimes used in treating FMS. GBP has a similar mechanism of action to PGB; it affects modulating neuronal voltage-gated calcium channels. It is used less than PGB (Northcott, Guymer, and Littlejohn, 2017).

1.3.1.2 Serotonin – Noradrenalin Reuptake Inhibitors

FMS patients have been found to have reduced concentrations of serotonin and norepinephrine in the serum and cerebral fluid (Ormseth et al., 2010). Serotonin and noradrenalin are implicated in the mediation of the descending pain inhibitory pathways linked to FMS's pathophysiology (Kia and Choy, 2017).

Duloxetine is a combined inhibitor of serotonin and norepinephrine reuptake. It is thought to be related to serotonin and norepinephrine reuptake inhibition in the dorsal horn's pain pathways (Wright et al., 2011). It weakly inhibits dopamine intake without significant affinity for histaminergic, dopaminergic, cholinergic, and adrenergic receptors. Duloxetine increases extracellular levels of serotonin and norepinephrine in different brain areas in proportion to the dose level. The analgesic effect of duloxetine is thought to be due to the enhancement of descending inhibitory pain pathways in the central nervous system (European Medicines Agency, 2015). Usual side effects are nausea, headache, palpitations, and flushing (Lunn et al., 2014). It is approved by the FDA for treating major depressive disorder, generalized anxiety disorder, diabetic peripheral neuropathic pain, and FMS (Wright et al., 2011). A meta-analysis with more than 2000 FMS patients from six randomized trials of duloxetine compared with placebo presented a significant improvement in a pain reduction at weeks 12 and 28 (Lunn et al., 2014).

1.3.1.3 Norepinephrine – Serotonin Reuptake Inhibitors

Milnacipran is characterized as an NSRI because in vitro studies have revealed that it has a three times higher efficacy for inhibiting norepinephrine reuptake compared to serotonin, which divides it from the SNRIs, which are more serotonin active (Ormseth et al., 2010). The imbalance of serotonin and norepinephrine in endogenous pain inhibitory pathways could lead to persistent pain. The increase in serotonin and norepinephrine may increase inhibition of painful signals and improve pain relief. The mechanism of action is not fully clarified (Cording et al., 2015). It is used to treat major depressive disorder and FMS (Cording et al., 2015). Based on clinical experience Milnacipran is recommended as the first – line medication for FM patients who experience fatigue and / or cognitive dysfunction (fibro fog) as the most limiting symptoms for them (Ormseth et al., 2010). Milnacipran is not approved by the European Medicines Agency but is approved in several European countries for treating other syndromes than FMS, such as depression (Northcott, Guymer, and Littlejohn, 2017).

SNRIs and NSRIs are recommended by the European League Against Rheumatism (EULAR) and Canadian guidelines (Lunn et al., 2014). Among all available treatments, Lyrica and Duloxetine are the most often prescribed medication to FM patients (Bidari et al., 2019). Selective Serotonin Reuptake Inhibitors (SSRI) and Tricyclic antidepressants (TCAs) are treatment options (Kia and Choy, 2017). However, opioids and anti-inflammatory medications are not recommended for treating FMS (Lunn et al., 2014). The findings suggest that FM patients have a chronically stimulated endogenous opioid system, resulting in lower regulation of opioid receptors. Besides, side effects often associated with opioid use, such as drowsiness, mental clouding, are likely to increase FM symptoms. Anti-inflammatory drugs work peripherally to reduce inflammation at the site of tissue damage. Given that the pain experienced by patients with FMS is not a nociceptive, drug has no particular benefit (Northcott et al., 2017). Cannabinoids, NMDAR inhibitors, dopamine agonists and other experimental agents are medications that require more study to assess efficacy (Lunn et al., 2014).

1.3.2 Non – pharmacological treatment

In general, physical exercises and cognitive behavior therapy (CBT) have the best evidence in the efficacy among the non – pharmacological treatment. It is of great importance that every step in managing and treating FMS is individualized to the patient’s abilities (Kwiatek, 2017).

1.3.2.1 Physical exercises

Physical activity plays a fundamental part in the process of treatment (Logar, 2011) and is the first-line nonpharmacological treatment for FM patients. Studies report a strong link between physical activity and quality of life, performance, and movement fatigue. It helps to maintain bone mass, improves strength, and reduces stress (Merriwether et al., 2018) (Merriwether et al., 2018). Current guidelines include recommendations for aerobic exercise (Larsson et al., 2015) with strengthening and stretching elements that are beneficial for reducing symptoms and hyperalgesia response (Okifuji and Hare, 2013). Initially, short–term physical activity for up to ten minutes every day is recommended. Improving physical fitness can be achieved through time; it takes about 3 to 6 months (Logar, 2011). Many patients are exercise intolerant due to pain; therefore, the patients must start at a low level with no significant distress present and gradual increase intensity (Okifuji and Hare, 2013).

The summary of Cochrane review reports about the effects of different types of physical exercise on FMS symptoms. Aerobic training (12-week exercise), of walking or stepping, was found to improve the general well-being and physical functioning but probably leads to little or no change in physical pain or tender points. While 12 weeks of strength training (lifting weights to 2.8 kg or using resistance machines) has been found to reduce pain, tender points, and depression, however, it does not affect the physical functioning (Busch et. Al., 2007).

1.3.2.2 Cognitive-behavioural therapy

Cognitive-behavioral therapy is a goal-oriented, short-term, and psychoeducational method for teaching symptom management and lifestyle change in everyday functioning (Bennet and Nelson, 2006). CBT is used to treat several health problems, including depression, anxiety, and chronic pain (Hassett and Gevirtz, 2009). The concept of CBT is based on the assumption that chronic pain and other FMS symptoms are maintained and influenced by emotional, cognitive (conscious intellectual activities such as thinking, reasoning, or remembering) and behavioral factors (Bernardy et al., 2013).

In general, CBT in patients with FMS does not provide lasting pain relief. Psychoeducation effects (information on the etiology of the disease, including the importance of psychological factors; treatment options; working mechanisms of psychological therapy) (Bernardy et al., 2013) changes the functioning and managing chronic pain and stress strategies (Bennet and Nelson, 2006). CBT's primary purpose involves improving the patient's sense of personal control over their pain, changing dysfunctional thought patterns and expectations involved in catastrophizing pain (Bennet and Nelson, 2006). CBT is based on changing behavioral patterns that encourage patients to take responsibility for managing pain and disability and attribute their successes to their efforts, through strengthening their sense of effectiveness (Taylor et al., 2016). Behavioral methods focus on identifying pain-dependent behaviors or events that alleviate pain and develop behaviors that depend on achieving goals related to the individual's values with pain. Patients learn new skills, such as relaxation techniques and activity pacing, to better manage their pain and develop different attitudes and more acceptance towards pain (Bernardy et al., 2013). Behavioral interventions of patients with FMS focus on improving mood, sleep hygiene, and problem-solving strategies perception (Hassett and Gevirtz, 2009).

1.4 IMPACT ON QUALITY OF LIFE

In general, life quality is considered a multidimensional concept involving a subjective perspective about the physical, functional, social, and emotional state of well-being. In patients with chronic pain, the medical applications influence the condition (Ofluoglu et al., 2005), patients report more dissatisfaction and less self – esteem with their bodies and with functional features than the general population (Martínez et al., 2018). The high negative impact on the quality of life could be best defined by the mental health state and psychological distress of FM patients that is higher than in patients with different other pain syndromes (Verbunt et al., 2008). They are likely to experience high levels of stress, anger (anger-in or anger suppression, anger-out or anger expression, and angry rumination), pain catastrophizing (excessive negative cognitive orientation to pain that provokes fear and discomfort and expends pain perception) (Galvez-Sánchez et al., 2019), as well as behaviors such as fear – avoidance and re – evaluation of beliefs (Bevers et al., 2016), which are linked to worsening of symptoms (Galvez-Sánchez et al., 2019).

FMS is a disorder with no outward signs, which leads to patients' concern about not being taken seriously (Arnold et al., 2008) and feeling stigmatized by their physicians and society (Sharon, 2006). FMS tends to be viewed as an "invisible disease" and patients often report the need to "defend" their health condition to family members and health care providers (Taylor et al., 2016). Their ability to maintain social relationships, fulfill family and work obligations, psychological and everyday functioning, as well as their mental health is negatively impaired by the syndrome (Galvez-Sánchez et al., 2019). They need more time and effort to complete an activity or are no longer able to perform it at all (Arnold et al., 2008). Due to unpredictable symptomatology, it is challenging and demanding to plan events and participate in social experiences. As a result, patients often feel insecure, judged (as unreliable), or are unable to establish and maintain social relationships. They often experience a loss of intimacy with partners and social isolation (Arnold et al., 2008). Accompanied symptoms, particularly depression and anxiety seem to considerably affect the stage of disability in FMS (Van Houdenhove et al., 2001). The disease's adverse effects also extend to the financial area of individuals, as they often find themselves in financial difficulties due to the decline in working capacity and high costs of health care (Sharon, 2006).

1.4.1 Personality and fibromyalgia

What are the primary factors that influence the development and persistence of symptoms? It appears that personality, as an integration of cognitive, behavioral, and affective patterns, is an essential modulator of a person's response to psychological stress (Malin and Littlejohn, 2012a). The proposed biopsychosocial model is connecting emotional distress, life events, and physical responses. Due to external social stressors, an emotional distress response occurs that influences and activates physical stress response. Personality, belief system, and other psychosocial factors modulate psychological response that could be linked to clinical features of FMS, so as observed negative pain beliefs and maladaptive coping techniques are each likely to be affected by personality (Malin and Littlejohn, 2012a).

There is no specific personality that could be defined as typical for FMS (Malin and Littlejohn, 2012a), but it seems that some personality features are more common in FM patients. Healthcare professionals typically recognize certain personality traits that they associate with FMS. For example, patients are described as perfectionistic, demending, introspective, and neurotic. These personality traits appear to contribute to the development and/ or persistence of symptoms, but the intricate connection between the disease's personality and the syndrome's pathophysiology remains unknown (Malin and Littlejohn, 2012a). Characteristic features such as obsessive – compulsive traits, perfectionism, neuroticism, "workaholism," self – sacrificing tendencies, and high achievement motivation appear to be related to an overactive lifestyle of coping with limiting depression and or anxiety. If these individuals are deprived of excessive activity as their coping strategy, for example, due to pain or functional limitations, the rate of psychological distress may increase (Verbunt et al., 2008).

Furthermore, the results of a study comparing personality features in females with FMS and healthy controls report differences in temperament and characteristics. Mainly low self – directness, high persistence, high harm avoidance, and high self-transcendence were present in FMS patients compared to the control group (Lundberg et al., 2009).

Another important factor influencing the experience of persistent pain and accompanying symptoms is the locus of control orientation. Patients with FMS have a higher tendency of locus of control, sources outside the individual control their experience, and experience a higher level of helplessness (Shuster et al., 2009).

1.4.2 Vulnerability factors in fibromyalgia

Certain factors seem to predispose a risk for FMS development, such as accidents, medical interventions or complications, emotional trauma (various forms of abuse or neglect) (Galvez-Sánchez et al., 2019), or a family history of FMS (Shuster et al., 2009). Studies in FMS patients reveal a link between childhood and adolescent trauma (adverse life events, such as violence, negligence) and the degree of disability in FMS. It seems that stressful life events may be associated with FMS development in later years, as early stress in the human developmental stage can affect the dysregulation of stress response mechanisms and affect brain modulation systems such as emotions and pain (Galvez-Sánchez et al., 2019). Studies have showen that FMS patients have a significant psychological distress background (Malin and Littlejohn, 2012b). Further studies are needed in this area, as the area is still relatively poorly studied (Galvez-Sánchez et al., 2019).

1.5 AWARENESS

The understanding of the world is perceived through our bodies. The phenomenon of body awareness is the key to understand the relationship between bodily symptoms and lived experience (Gyllensten et al., 2010). The term "body awareness" has emerged as a matter of scientific research across different health issues. Although a precise definition is rarely given, body awareness requires an attentional focus on and awareness of internal body sensations (Mehling et all, 2009). It is a concept that includes various aspects of the experience so as the knowledge needed to move our body through space, to interact and connect with other objects to know that our body is ours and not foreign, and awareness and ideas about our body how we feel about it. These experiences intertwine and complement each other in everyday life, and the fact that we experience our body it becomes almost self-evident (Valenzuela-Moguillansky, Bouhassira and O'Regan, 2011).

Body awareness is the sum of a phenomenological aspect of interception and proprioception when entering conscious awareness and is modified by attention, interpretation, beliefs, memories, affect, and attitudes (Gyllensten et al., 2010). Body awareness is related to the concentration of attention and awareness of internal bodily sensations. The term is often used in anxiety and panic disorder studies to describe cognitive attitudes, where the patient is defined by excessive focus on physical symptoms, enlargement (somatosensory enhancement), rumination, and beliefs about catastrophic outcomes, and is closely associated with adverse clinical outcomes such as the path of pain (Mehiling et al., 2009). The experience of pain is closely related to the sense of the bodily self, it disturbs the sense of the bodily self, and in turn, it changes the experience of pain (Valenzuela-Moguillansky, 2013).

Body awareness is a dialectic process between living or being in the body and becoming aware of the lived experience. Marleau-Ponty (1962) said that the body is, at the same time, subjective and objective, the lived experience is personal and existential (Marleau-Ponty, 1962 in: Gyllensten et al., 2010). Two concepts are commonly referred to as body awareness, interoceptive awareness (body image), and exteroceptive awareness (or the body schema) (Martínez et al., 2018). Both types of awareness are essential for an internal representation of our body, the posture, and moving (Valenzuela-Moguillansky et al., 2017).

The conceptual construction of a "body schema" is viewed as a dynamic representation of the body that reflects the position and movement of the body in space and real-time. The information is obtained through sensory input and related to the motor system to physically gain control over action (Martínez et al., 2018). Meanwhile, the "body image" refers to a conscious cognitive representation of the body, maintained by ongoing tactile, proprioceptive, and visual input. It can be modified by memory, beliefs, and psychosocial factors (Valenzuela Moguillansky, 2012). Interoceptive awareness is described as the conscious perception of one's inner state and the sense of the body's physiological condition. It can show the relationship between the body's organic function and the person's mental and emotional experience (Valenzuela-Moguillansky and Reyes-Reyes, 2015) and so it is a significant factor in studying the relationship between body and mind. Exteroceptive body awareness is defined as our body's knowledge of movement and space. It results from integrating exteroceptive signals (vision, touch, sound), proprioceptive, vestibular systems, and voluntary motor systems. The pain experience is an embodied one (Martínez et al., 2018), the relationship between body perception and pain is examined from different perspectives. The continuance of body image and body schema depends on multisensory body inputs. Increasing evidence reveals that patients with chronic pain may alter their body schema and body image (Martínez et al., 2018). One perspective highlights the role of attentional biases away or toward the pain location; another view underlines the importance of multisensory body representation and the surrounding space in pain perception. It is a complex networking between motor action and pain perception (Valenzuela-Moguillansky et al., 2017).

Patients with long – lasting pain often report feelings of missing confidence and trust in their body (Courtois et al., 2015), together with feelings of anxiety and depression (Gyllensten et al., 2010). FM patients reports show that pain loci are different from patient to patient and change from one day to another. However, the presence of pain and fatigue is felt over the whole body continuously (Valenzuela-Moguillansky et al., 2017). Therefore, FMS has an essential impact on one's relationship with their body, the body image is changed and disturbed (Martínez et al., 2018). It becomes a salient and unfamiliar presence that affects every day functioning, social relationships, and quality of life (Valenzuela-Moguillansky et al., 2017).

A 2018 study by Martínez and colleges examined embodied pain in FM patients, more exactly disrupted bodily representations, and increased body schema plasticity. Essential findings that are related to our research is that spatial representations as part of the spatial experience associated with the body derive from on-line afferent somatosensory inputs arising from short-term memory and embodied information stored as long-term memory. Research on eating disorders proves that in the case of disturbed interactions between somatosensory inputs and offline representations of the body, the stored frame of reference cannot be adjusted accordingly. The individual becomes chained to negative representations of her body; a model termed as an allocentric lock. The amygdala and the complex hippocampal connection play an important role, where long-term hardened emotionally intense perceptions are expected to be enhanced. An inadequate updating of stored, negatively biased somatic representations may be crucial (Martínez et al., 2018).

1.6 PURPOSE AND OBJECTIVE

Various aspects of FMS are still unknown. FMS has a significant impact on patients, their quality of life, functioning, social relationship, and relationship with their bodies. Chronic pain, fatigue are often associated with psychiatric symptoms (depression and/or anxiety).

The purpose of the thesis is to contribute to an in-depth understanding of the experience of pain and other symptoms of FMS as a chronic pain syndrome and to understand the process of coping with FMS. At the same time, we want to contribute to the explanation and understanding of the effect of awareness of one's own physical condition, development, and acceptance of the disease in patients with FMS. We are interested in investigating the bodily experience of fibromyalgia symptoms from a phenomenological perspective. We believe that this area is still relatively unexplored and needs different research approaches.

Phenomenological research is a qualitative study method based on philosophical starting points (Neubauer et al., 2019). Qualitative approaches' philosophical basis originates from phenomenology (as a philosophy), existentialism and hermeneutics. According to that there are different types of phenomenology, with different characteristics: descriptive or hermeneutical-refering to the study of personal experience; eidetic or transcendental, and genetic or constitutional phenomenology (Padilla -Diaz, 2015). The primary objective of phenomenology is to describe and understand the meaning of the individuals lived experience; in terms of how it was experienced and what was experienced. Through examining a subjectively lived experience, new meanings and appreciations can be made how we understand the experience (Neubauer et al., 2019). The object illuminates the phenomenon that we are interested in, with regard to the experience's basic structure. Phenomenons are described based on data obtained from oral or written personal experience reports (Kordeš and Smrdu, 2015).

1.6.1 Goals of the master thesis

Based on the literature, we formulated goals that are divided into general and specific. The overall goal includes in – depth insight into patients' recovery experience with fibromyalgia syndrome and research into the importance of physical awareness in the recovery process. We want to acknowledge (understand) the concept of recovery in the context of a chronic disease such as fibromyalgia.

To have a more in – depth insight into the process of the course of the disease and recovery, we defined a specific goal. As part of learning about experiencing the process of treating patients with fibromyalgia, we focused on experiencing particular situations. Through this, we want to examine the structure and significance of key moments. Key moments refer to experiences that are of great importance to the patient in the disease process. While studying the experience, we focused primarily on body awareness in the disease's evolution and recovery.

1.6.2 Reasearch questions

In the qualitative-quantitative research, we focused on four research questions, to which we wanted to obtain answers through micro-phenomenological interview and body – mapping methode:

What and how do people with fibromyalgia syndrome experience in connection with the disease, in the process from the onset of symptoms to the present moment?

How do people with fibromyalgia syndrome cope with this disease?

What are the key factors that worsen or improve the symptoms of the disease in people with fibromyalgia syndromes?

How does the importance of physical awareness contribute to the recovery process, and what does the recovery process mean for an individual?

2 METHOD

2.1 PARTICIPANTS

We conducted a qualitative-quantitative study, which included six participents, all adult females, between 30 and 60 years old. When including in the research, we considered the inclusion and exclusion criteria for their selection. The inclusion criteria were adulthood, a formally confirmed diagnosis of FM, and a willingness to participate in the study, with the key being that they had a desire to explore their experience. Exclusion criteria included emotional disturbance, such as severe emotional disorder (major depression and anxiety), and the presence of severe acute pain that causes physical disability. The participants of the research were obtained through the Institut of clinical psychological Izola and by the method of chain sampling through the participants who consented to the research. Due to low prevalence, male FM patients were not included. Every participent recived an information sheet and provided written, informed consent to participate. Participation in the survey was voluntary and anonymized. With the consent of the participants before the start of the research, they permitted all the obtained and anonyme data to be used for the purposes of the research of the master's thesis.

Despite the fact that the main research method was a micro-phenomenological interview, we cannot claim that all the interviews meet its definition. Some interviews reach only the criteria of phenomenological interviews. Kordeš and Demšar (2021) argues that it is essential in all interviews related to phenomenology, specially micro-phenomenology, that the participant is taught observation, that more in-depth descriptions can be obtained. Usually, no one teaches us to observe our own experience, introspection, and reporting on it. FM patients usually resort to ways to pay less attention to themselves and act according to high performance. Not knowing and describing oneself and the experience can be an additional problem in obtaining in-depth data consistent with phenomenology (Kordeš and Demšar. 2021).

Five of six participants underwent all four sessions and an anamnestic interview. Participant two conducted only an anamnestic interview and one positive session of in-depth experience research. Due to personal problems, the participant did not maintain the other three meetings. Due to the large amount of data obtained, we did not add an additional participant.

Table 1

Socio-demographic characteristics of participants

Variables	
Number of participants	6
Gender	female
Disease duration	min duration 2 years; max duration 11 years, since diagnosis
Mean age of patients	54
Family status	married 4; living with a partner 1; single 1
Employment situation	full-time work 2; self-employed 1
Registered disabled	retired on medical grounds 3

For the protection of personal data, each participant was assigned a code. For example, the first participant is classified under code U1, the second participant U2, the third participant U3, the fourth participant U4, the fifth participant U5 and the sixth with U6.

The codebooks and grounded theories contain citations, where, in addition to the participant, a number is given that presents the number of the interview. E.g. code for the first micro-phenomenological interview with the first participant: U1-1. Statements containing only participant code (UX) are examples from anamnestic interviews.

2.2 MATERIALS

The quantitative part of the research included the BDI (Beck Depression Inventory) and MAIA (Multidimensional Assessment of Interoceptive Awareness) questionnaires. The main techniques of the reasurche is the qualitative part, involved a micro-phenomenological interview and the body mapping technique.

2.2.1 Beck Depression Inventory

The BDI questionnaire is one of the most used scales handled for evaluating the severity of depression in adolescents and adults. The usefulness of the questionnaire ranged from the general population to the field of clinical practice (Lee et al., 2017) and is applied also for research purposes (Garcia – Batista et al., 2018). The questionnaire, developed by Aaron T. Beck in 1961, contains 21 sub-questions (Lee et al., 2017). Higher scores of 21 self – reported items shows higher levels of depression (Garcia – Batista et al., 2018). The questionnaire was originally developed in English and was later translated into multiple European languages, Arabic, Chinese, Japanese, and Persian, with high levels of reliability across cultures (Lee et al., 2017). The first major revision was made in 1966 and was named BDI – IA. Later in 1978, the second main revision was made as to the BDI – II (Lee et al., 2017). Over the years, there were made many studies about the validity and reliability of the self–reported questionnaire. The results have shown acceptable internal consistency and high reliability (Garcia – Batista et al., 2018). The internal compliance coefficient of the questionnaire reaches a value of 0.91. The reliability of the original questionnaire in English is 0.89 (Farinde, 2013). The questionnaire was used only to confirm the selection of participants, to comply with the exclusion criterion of severe mood disorder.

2.2.2 Multidimensional assessment of interoceptive awareness

The MAIA self – report questionnaire is a multidimensional assessment of interoceptive awareness, consisting of 32 items, where eight categories are assessed on a six-point Likert-type scale (Miheling et al., 2012) of ordinal responses coded from 0 (never) to 5 (always). The instrument was designed to understand the interoceptive awareness (Valenzuela – Moguillansky in Reyes – Reyes, 2015) and detailing alterations in interoceptive body awarness in FM patients (Valenzuela-Moguillansky, Reyes-Reyes, and Gaete, 2017).

The instrument consists of eight categories 1. Noticing: it is the awareness of comfortable, uncomfortable, and neutral sensations, 2. Not-Distracting: the tendency to not distract from feelings of pain or discomfort, 3. Not-Worrying: the presence, absence, and extent of emotional distress or worry while feeling pain or discomfort, 4. Attention regulation: the skill to maintain the attention on body sensations, 5. Emotional awareness: understanding the relationship between emotional state and body sensations, 6. Self-regulation: the skill to control psychological stress by focusing on body sensations, 7. Body listening: being aware and listen to the body, and 8. Trusting: feeling the body as a safe and trusting place (Valenzuela – Moguillansky in Reyes – Reyes, 2015).

The questionnaire was developed by the authors Mehling and college in 2012 (Miheling et al., 2012). It was translated into nine languages. It was developed systematically through reviewing the current literature, framing a multidimensional concept, developing items, and analyzing responses to items by body awareness – enhancing therapies (Valenzuela – Moguillansky in Reyes – Reyes, 2015). The conceptual framework is based on mindfulness, broader awareness focus on thoughts and exteroceptive stimuli, and a more specific focus on inner body sensations. Its aim is in interoception research and for the assessment of mind-body therapies (Mehling et al., 2012).

The reliability of the Cronbach's alpha questionnaire was assessed for six of the eight categories (observation, attention regulation, emotional awareness, self-confidence, regulation, body listening, and trust) ranging from 0.76 to 0.92. The subscales "Not-

Distracting" and "Not – worrying" are placed in the questionable range (α = .62-.67) (Brown et al., 2017).

The MAIA questionnaire has not yet been translated into Slovenian, so it was necessary to translate it and make a back-translation from English to Slovenian. This was followed by comparing the adequacy of the translation of the items, and then three individuals who were not participants in the main research were asked to complete a questionnaire and asked for feedback on the comprehensibility of the items. Based on their responses, additional items were further revised if necessary.

2.2.3 Micro-phenomenological interview

The central techniques in the reasurch of the master thesis are micro-phenomenological interview and body mapping. Micro-phenomenological interview is defined as a first – person research for studying experiences. The phenomenological approuch, created in 1994 by Pierre Vermersch, is mostly used in the cognitive science (Valenzuela-Moguillansky and Vásquez-Rosati, 2019). A large part of our activity and experience usually remains unnoticed, it is experianced in a "prereflective" way. Through special acts, as precise prompts and questions, we try to trigger a person to empathize with a certain lived experience and subjectively express a previously unrecognized part of their experience and describe it in detail (Petitmengin, Remillieux, and Valenzuela-Moguillansky, 2018).

The exploration of a singular concrete experience makes it possible to suspend our preconceptions about the experience. It affects our way of thinking, by redirection our attention from the absorbtion into the contetnt of experience (the "what") towards the way this experience appears to us (the "how") and its structural characteristics (Petitmengin, Remillieux, and Valenzuela-Moguillansky, 2018).

By choosing this method, we want to obtain the most accurate description of a single experience (Valenzuela-Moguillansky and Vásquez-Rosati, 2019). Participants are guided to empathize with real experiences that significantly impact them (Glaser and Strauss, 1967), so a detailed description can be obtained focusing on the procedural dimension and embodied perspective. The interviewer leads the interviewee to the evocation of a specific experience. In these contexts, evocate means the process of the interview's sensory-motor contact with the specific experience (Valenzuela-Moguillansky and Vásquez-Rosati, 2019). The past situation becomes more vivid than the present situation is redirection. General descriptions of the situations are to be avoided as well as judgements, explanations or theoretical knowledge about it and believes of the specific experience (Valenzuela-Moguillansky and Vásquez-Rosati, 2019).

The qualitative text analysis aims at the grounded theory, which is based on the coding process (Kordeš and Smrdu, 2015). The inductive abstraction process involves recognition guidelines and guidelines on establishing relationships between them (Petitmengin, Remillieux, and Valenzuela-Moguillansky, 2018).

2.2.4 Body Mapping

The technic of body mapping is defined as the process of creating an image of the natural size of the body in which various aspects of the human experience are graphically represented according to the phenomenon being studied (in the case of research of master thesis, these are key moments in the disease treatment process). It is based on the premise that the importance and weight of a story can only be understood concerning an individual's overall experience, including the physical. It represents a creative way of telling a story with the help of various symbols that individuals attach to their life circumstances and enables creative expression of their own embodied experiences and meaningful attributes. The body imaging technique was developed in South Africa in 2002 by a clinical psychologist Jonathan Morgan at the University of Cape Town. Primarily it was designed as a method of art therapy for women infected with HIV/AIDS. General guidelines for visual analysis include reflexivity, which is key to authentic interpretation. The analysis is intended to assess the participant’s in-depth insight into certain aspects of their logic, tendencies, desires, material circumstances, and behavior (Gastaldo idr., 2012).

There were several arguments for the use of body mapping as part of the research. The technique provides adequate access to people's perception of their body. It is a holistic method that encompasses the mind, physical experience, and social context. Thus encouraging participants to think about the relationship of their thoughts, bodily sensations, feelings and experiences. Body mapping provides a nonverbal method for expressing experiential states, such as pain, discomfort and frustration, which are difficult to express verbally (Skop, 2016). In sustaining a coherent epistemological perspective, we assume that participants are reflective individuals who participated in the study because they wanted to share their stories with others and gain a deeper insight into their experience (Gastaldo et al., 2012). Necessary accessories are flipchart sheets and drawing material such as crayons, and pencil. In our study, we used the body mapping method as a data generated research tool, supplement to micro-phenomenological interviews.

2.3 PROCESS

2.3.1 Informed consent to participate in the research

Before starting the research, participants signed a consent form to participate, where they agreed that they were aware of the survey, participated in it voluntarily, and aware that they have the right to conclude the research at any time. They also signed a consent for the audio recording of micro-phenomenological interviews, semi-structured anamnestic interview, and conversation during the creation of body maps. The recording made the data analysis process more accessible and more accurate. After transcribing the transcripts, all the recordings were destroyed.

2.3.2 Ethical considerations

The research was conducted in accordance with the principles of the Code of Professional Ethics for Psychologists and the provisions of the Declaration of Helsinki. Accordingly, participants will be reminded that the data of all data retrieval techniques are protected, remain anonymous as participants, asked for permission and signed consent to record conversations. The protection of personal data was ensured by encrypting participants with codes. Participant codes were separated from actual data. All information that could reveal the identity of the participants has been changed or deleted. The author of the research keept the recordings of the interviews and their transcripts and destroyed them after transcription. Due to the protection of personal data, transcripts are not published. The results contain quotations from the participants to display the contents, but their identities or personal data are adequately concealed. Besides, we payed attention to the possible adverse effects of reliving individual moments, which will give participants the opportunity for additional clinical psychological, and psychiatric support.

2.3.3 Preparation, conduct of interviews, recording and transcription

Qualitative- quantitative research included six primary sets of processes: introduction, semi -structured anamnestic interview, relaxation exercise, micro-phenomenological interview along with body mapping technique, and ending of session. The length of each meeting was estimated at two hours, but the duration of the interviews and body mapping were, if necessary, adjusted to the needs and nature of the functioning of each participant. In the first introductory part, we explained to the participant the purpose, course, procedure, and method of work. This was followed by the signing of two informed consent forms. Then we conducted a semi-structured anamnestic interview with each participant, where we obtained their medical history and other relevant personal information. The participant were given the two questionnaires: BDI, and MAIA, which aimed to further assess the emotional state and the impact of fibromyalgia syndrome on lifestyle. The primary purpose of the first meeting was to review the disease process, and identify key moments. The participant summarized the evolution of the symptoms by drawing the path of the disease process, including the key moments. We asked them questions related to the social-emotional context in which symptoms began, actions and reactions to diagnosis, self-care measures, changes in interpersonal relationships, work, daily life, and the path of medical consultations. During the interviews with the participants, various topics were opened and developed that we did not anticipate in the interview planning, as the interview was semi-structured. Together with the participants, we defined up to four key moments, trying to find both the moments that worsened and those that improved the symptoms of the disease.

In the following four meetings, we used the method of micro-phenomenological interview, the aim of which is to obtain more detailed descriptions of the experience of key moments, which we defined together with the participant at the first meeting. The micro-phenomenological interview technique was used in conjunction with the body mapping technique. Body imaging was performed after each micro-phenomenological interview for each selected key moment. The session was ended with a conversation about the participant’s experience of the research process and about her well-being to ensure that the participantes left each meeting without negative feelings.

After all the meetings were completed, the participant resolved the MAIA questionnaire to compare the initial answers and ensured that the participant's condition did not deteriorate in any way due to the research. The interviews took place in the Institute for clinical psychology Izola and in three cases at the participants' homes. In all cases, we provided privacy and a quiet space for conducting interviews without disturbing stimuli.

2.3.4 Data analysis

After all of the interviews were transcripted, we started analyzing the data. All interviews transcriptions were first read independently by the two researchers, who then compared and combined their analysis and gained an idea into the data. Using the micro-phenomenological method, we obtained 21 transcripts of interviews and 6 transcripts of anamnestic interviews. In the analysing process we followed the principles of the grounded theory, where similar data, obtained through coding, are arranged, and conceptually marked. Concepts are categorized and organized by conditions and relationships. Then follows the formation of dimensions and lastly the development of a grounded theory (Willson Scott, 2004). It consists of four phases of coding: initial coding, focused, axial coding, and theoretical coding (Kordeš and Smrdu, 2015). Initial coding is the beginning of data analysis. By comparing the obtained data, we gained insight into the participants' crucial areas and addressed them analytically. In the initial coding phase, we coded the data as descriptively as possible and summarized the participants' experiences. Data were coded with behavioral descriptions and verbs, so the codes were based on the experience of the participants. Based on the obtained codes, we combined the codes into more according to the similar general and abstract categories in the following steps. While analyzing new transcripts of interviews, we were proceeding to create new codes and modify existing ones to summarize the experience. In this way, we discovered new topics in the data. The next phase was followed by focused and axial coding. In this coding phase, we collected the most common and essential codes and interconnected them. The obtained codes were based on a similar importance and grouped into broader categories, which holistically answer the research questions. Theoretical coding represented the last phase of the analysis. At this stage, we looked for relationships between categories and subcategories. Based on the mutual comparison, we tried to describe the obtained codes as much as possible and connect them into a meaningful theoretical model. During the analysis, we returned to the previous phases several times and thus intertwined them. By multiple coding, we tried to adjust the acquired concepts to the participant's experience to ensure the results' validity. In all phases, the author of the research analyzes collaborated with the mentor and co-mentor of the research, who directed her on obtained codes and categories.

In addition to transcripts, we also analyzed the participants' body maps. There is a lack of literature in the field of visual analysis of FMS experience, so we refer to the explanation of Gastaldo et al. 2012), who states that images are analyzed in their entirety, including the process of creation (verbal and fieldnotes), the body map itself, and the narratives that accompany the design of the method (Gastaldo et al., 2012). All images were photographed with a camera and uploaded to the author's personal computer, which offered as an organization system. We designed a visual coding scheme. It included several stages. We first followed an inductive approach of studying all body maps (as if one were reading transcripts several times) to get acquainted with data. The understanding of this was based on the verbal narratives of the participants while forming body images. Our central goal was to highlight the differences between factors that occur in a positive situation and those present in negative situations. We generated the source code based on similarities and differences in colour, themes and discourses, species presentations (for example, words, pictures, image shapes), size, and location (for example, symbols), elements of drawings.

3 RESULTS

In the master's thesis, we examined the in-depth experience of pain and other symptoms of fibromyalgia as a chronic pain syndrome. We were interested in understanding the process of coping with fibromyalgia syndrome. At the same time, we wanted to use the obtained results to contribute to the understanding of the effect awareness of one's own physical condition, development and acceptance of the disease in the recovery process in patients with fibromyalgia and wanted to acknowledge the concept of "recovery" in the context of a chronic disease such as fibromyalgia. We wanted to study and understand the main factors that worsen or improve the symptoms. The results present the categories and subcategories (as subordinate divisions of categories) obtained in the process of qualitative analysis and the codebook, where all the categories are described and explained in more detail, also with the help of examples. To facilitate the overview, the obtained categories and subcategories are also collected in overview tables. The results of the MAIA questionnaire (Multidimensional Assessment of Interoceptive Awareness) are also presented, according to the individual participants, before and after the survey.

3.1 CODEBOOK 1

The specificity of fibromyalgia is manifested in complex symptoms, which are often difficult to prove with medical procedures and examinations that we know so far. A key tool we can rely on is people reporting their well-being and experience. In my master’s thesis, we examined the in-depth experience of pain and other symptoms of fibromyalgia as a syndrome of chronic pain. The main factors that may worsen or improve the experience of the symptoms were considered and further explained. With the in-depth study of the people’s experience within the scope of fibromyalgia, we investigated the factors of positive and negative experiences with a phenomenological approach, namely with the method of the interview. With the participants, whose symptoms were expressed to a lesser extent or the symptoms were absent, we researched the experiences individually. We also scrutinized the situations where pain or otherwise feeling unwell were more profound, such as overall physical fatigue, impaired cognitive function, and other symptoms. At the same time, we wanted to contribute to the understanding of how the perception of one's own physical state, the development, and acceptance of the disease in the recovery process, affects patients with fibromyalgia.

Figure 2

Categories of the key factors that improve symptoms of the disease

Categories	Subcategory	Notes
Social acceptance	Understanding	
	social connection	
Experiencing one-self	Self-worth	Diametrically opposed to the category of *Low self-*
	Self-awareness	

		esteem as a factor in a negative situation.
Experiencing relief	Unburdening	Diametrically opposed to the category of *Sense of over-responsibility* as a factor in a negative situation.
	Alleviation	
	Feeling rejuvenated	
Mental clarity	Focus of thoughts	Diametric opposition to the category of *Fibro fog*, as a factor of the negative situation.
Presence in the moment	Focus on the here and now	The category is internally very uniform, so it does not contain a subcategory.
Experiencing pleasant emotions	easing	
	pleasure	
	Gratitude	
	Absence of fear	
	Joy	
Pleasant physical well-being	Physical improvement	
	Physical lightness	
	Pain-free condition	
	Redirected body perception	
The experience of freedom	Hope	The category of experience of freedom subtly connects other categories, but in connection and comparison with the other categories, such as *Sense of over-responsibility*, it differs in intensity. The examples are slightly less clear, as the sensitivity of the category makes it difficult to cite actual examples. Although not entirely explicitly stated, but clear from the context and experience, a category
	Inner peace	

		could be formed and summarised.
Connection with the environment	Perceiving environment	
Empowerment	Setting boundaries	It stems from rare situations where people have changed from the originally negative situation to a positive experience, with altered and assertive behaviour,

The enumerated categories represent the parent concepts to the individual codes. By analysing 11 micro-phenomenological interviews of in-depth research of the positive situation, the following 10 categories were discovered: *Social acceptance*, *Experiencing one-self*, *Feeling of relief*, *Focused attention*, *Presence in the moment*, *Experiencing pleasant emotions*, *Pleasant physical well-being*, *Experience of freedom*, *Connection with the environment*, and *Empowerment*. In the continuation, description of the named categories will be presented and supported by representative excerpts from the participants' interviews.

Category: Social acceptance

Subcategories: *understanding* and *social connection*

The category *Social Acceptance* contains the subcategories *Understanding* and *Social connection*. It represents an important factor in the positive experience of the participants. Within the subcategory of *Understanding,* the participants describe the feeling of not needing to explain and defend their feelings to others, they feel accepted and understood, and at the same time they feel that others comprehend, accept, and allow their feelings and desires to be expressed. In a given situation and relationship, they feel safe and the social environment feels like home. The subcategory of *Social connection* includes the participant’s senses of verbal, nonverbal, and physical connection with those present in a situation. The nonverbal connection is manifested in the fact that persons understand each other without the use of verbal communication. They understand each other’s personal physical limitations, are empathetic, and sympathize with each other. By deepening the connection, harmony is formed with the other people present, also covering a wider spectrum of both humans and animals. People perceive this as an energy that fills the body. The differentiation of the perception of feelings on the physical level deepens, they also feel a pleasant warmth in the body and a reduced intensity of the burden brought about with worrying. Also, the intensity of the perception of pain and other symptoms of the syndrome is lower than before. In such a situation, attention is focused on the subject with whom the interaction takes place.

U1-2: *In a sense it's like understanding each other without saying much. Because in principle we didn't really chat out loud at the gym, but somehow, we knew about everybody because we knew what problems any of us had with certain exercises, some more than others, sort of like that.*

U5-2: *I take her in my arms and we dance together. I feel like something pleasant taking over me. First, I feel it all over my body, which becomes lighter. Then I also feel it in my head, my thoughts calm down. There is nothing but positive energy.*

U1-2: *I don't know. Also, verbally, because everyone has always found some encouragement at a given moment, one, I don't know, one understanding word. You always had the feeling that someone knows how you feel. Without you explaining in detail there. Basically, you didn't have to make any effort to get through to somebody all the time.*

Category: Experiencing one-self

Subcategories*: self-worth* and *self-awareness*

The category of Experiencing one-self (also: high self-esteem) includes the subcategories of perceiving *Self-worth* and *Self-awareness*. Self-evaluation tells us how satisfied the participants are with themselves, whether one evaluates oneself positively or negatively, and to what extent we accept ourselves as who we are. Within the subcategory of perceiving *Self-worth*, persons describe a positive evaluation of themselves, namely they are aware of their value in a certain situation, e.g. that they are worthy and good individuals and that their work is important. When people are *Self-aware* they have attention focused on themselves. This is reflected in the experience of one's own body, thoughts, and emotions. They are confident in themselves and act a little more decisively.

U5-2: *Attention is not just focused on her. It's focused on me too. I know I'm feeling good then. I am connected to her and to me. At that moment, I am totally aware of myself.*

U3-3: *In that moment, I feel like I exist. That's why I also act so confident and determined that the person sees that I mean business and there is no other option left.*

U1-4: *Basically, I am the core. Everything comes from me. This breadth, this greatness, this ease.*

Category: Experiencing relief

Subcategories*: unburdening, alleviation*, and *rejuvenation*

The category of experiencing relief is accompanied by a reduced sense of responsibility in connection to the notion that people have fewer "rules" that need be followed and a reduced feeling of obligation to do something (therefore opposite to the sense of “I have to” or “must”). They describe these feelings as if such burdens have fallen off their shoulders. The behaviour follows their own desires and emotional states rather than the desires of others, as is usually the case. A belief that everything is in order with the world is present. Relief contains the subcategories of *Unburdening*, *Alleviation* and the feeling of *Rejuvenation*. In the subcategory of unburdening, subjects describe feelings when they are not trapped by their own burdens and there is no saturation of thoughts – the flow of thoughts is calmer and at ease. The subcategory of *Alleviation* is most pronounced at the level of the body, as a feeling of weightlessness, softness of the whole body, and absence of physical tension. Feeling of *Rejuvenation* is reflected in the fact that people feel child-like playfulness and can step out of their typical social role.

U2-1: *All burdens fall down. I mustn’t, I’ve learned that burdens have to stay at home when I get on a motorbike I mustn’t think. I let myself go with the flow, that kind of nature. It’s not about thinking if it hurts me or will hurt me, there’s just no worries. I forget about everything.*

U3-2: *There are no rules I have to follow. There's absolutely nothing I need to do there. I don't need anything on the boat if I don't want to. I actually go into the water very rarely. That was completely weird to him, so I told him, look, I don’t bother with it. If I feel like it, I go, and if I don’t feel it, I don’t go, for me both options are just as good. Now forcing myself to go into the water just because I have water in front of my nose, seems pointless.*

U3-3: *Everywhere, all over my body, I feel relief. It is one of those feelings, like when you jump into water, head-first into the water. Jumping into the sea is like jumping onto feathers. Somehow it seems as something overwhelming me. From the toes on my feet upwards.*

Category: Mental clarity

Subcategory: *focus of thoughts*

The category includes the participants' descriptions about improved functional concentration and effective cognitive functioning, which includes: a sense of mental clarity, ease of thinking, lack of mental saturation, and following the mental flow more easily. In the situations described, the concentration of the observed subject improves compared to their previous functioning, they describe this as the ability to function normally again. They are not overwhelmed with worries and highlight the change of feeling of cognitive coherence with the experience. They perceive their thought flow as being in control and directed by themselves.

U1-2: *As if, I don't know ... I am, maybe, more collected. Because before this period, my head didn’t work, even now it doesn’t every day. But back then, it’s as if one part of those functions of yours ... as if ‘You’ return back, as if something comes back that makes you more composed, more focused.*

U5-2: *Thoughts are shorter and nice. All in all, the whole thing seems clearer to me, despite the fact that there are a lot of thoughts, but they are all focused on something beautiful now. Well, at least the difficult concerns that are often present, are no more*.

U4-4: *This energy of relaxation radiates mainly downwards. In the head, however, it appears above all as this emptiness and consequently as a kind of clarity. Despite the thoughts are not many, they are different than usual. There is none of the saturation.*

Category: Presence in the moment

This category is broader and holistic because it encompasses both the experience of the world and the experience of one’s self, which encompasses both the specific way and the content of thinking, as well as emotions and physical well-being. At the same time, the category is so compact and the elements listed are so intertwined that additional parsing could change the holistic integrity of the experience, which is crucial here.

The participants describe the absence of worry, and the ability to be more present in the moment. They describe their awareness of their presence from moment to moment. This is accompanied by an attitude of acceptance, openness and curiosity. They describe the awareness of the ‘*now’* as a moment in which *accepting* and *releasing* the experience at a certain moment alternate. They do not cling to an individual experience, but merely leave it as it is. They describe experiencing pleasant emotions, less worry, and less intense pain with increased attention directed to the present moment.

U5-2: *Lightness is equally pronounced throughout the body. Pleasant, no tension. But I experience the most positive emotions in my head. I am completely focused on the moment. It makes me so happy being in that moment that it stops me completely in an instant.*

U6-4: *Attention is focused only the situation – we drink coffee together, the dog is jumping about, and we laugh. It's nice.*

U2-1: *No worries, nothing, I'm watching what's going on. There are no everyday worries, you automatically indulge in driving and look around at what is and how it is. There are no worries. You sit up, looking left and right. You release.*

Category: Experiencing pleasant emotions

Subcategories: *easing, pleasure, gratitude, absence of fear,* and *joy*

The category includes the subcategories *Easing*, *Pleasure, Gratitude*, *Joy*, and *Absence of Fear*. Mood levels are elevated, people have fun in interpersonal relationships. The subcategory of *joy* is predominantly described through behavioural responses of laughter. To a greater extent the participants perceive *easing* and *pleasure* on a physical level, while *Gratitude* and the *Absence of Fear* are experienced on an emotional level. Awareness of *Gratitude* is usually present during physical well-being, where less intense pain is present, and during pleasant interpersonal relationships. With *gratitude*, attention is more focused on positive experiences, and the perception of emotions that are positive for the participants, is increased. In the *Absence of fear*, they no longer feel that they will not be able to perform the intended tasks. They also experience emotions on a physical level. E*asing* and *Pleasure* are present throughout the body, which participants most often perceive as a pleasant feeling of warmth.

U5-4: *I feel thankful that I was able to experience this. The head is eager and full of joy. I am grateful and happy to be able to watch the children laugh. I am aware that I am a happy individual.*

U1-2: *Maybe there is no more of the fear of not being able to do something.*

U4-4: *The body is relaxed, in some sort of comfort that sways you.*

Category: Pleasant physical well-being

Subcategories: *physical improvement, physical lightness, pain-free condition,* and *redirected body perception*

The category includes descriptions of absence of pain and overall fatigue. The movements become lighter, there is softness present all over the body, more energy, and a greater feeling of strength and easing. This kind of physical condition is accompanied by joy. The category includes the subcategories of Physical Improvement, Physical Lightness, Pain-Free Condition, and Redirected Body Perception. People are aware of their body, but some participants perceive it to be slightly altered as attention is diverted. The body is relaxed, light and does not represent an obstacle for them to interact with the outside world. When the subject is aware of her body, there is a feeling that the body does not exist or that individual parts of the body are not part of the whole. This is related to the feeling of lightness of the body part, which is perceived as different or separate from the whole. The experience is perceived as unusual, as most of the time the feeling of body tension is present. In some cases, they report experiencing a state of complete absence of pain and fatigue.

Note: The women participating rarely reported a changed sense of ownership, but due to the specific nature of the experience, it is important to highlight it nevertheless.

U1-4: Yes, in the legs, on the back. The legs are light. They’re not heavy. When I swim it’s like they’re not mine, weightless, we could say.

U1-2: I feel improvement in the muscles all over my legs, a sort of energy, I don’t know. Energy, strength to be able to move more relaxed again. Maybe there were too many of these words before: ‘Watch out for this, watch out, what if I can’t, what if…’.

U5-2: I am well aware of myself. But my body feels like it’s not. As if nothing is stopping me from my joyfulness. But I know, there is a body.

Category: Experiencing freedom

Subcategories: *hope* and *sense of inner peace*

Within the category of *Experiencing freedom,* the participants describe the experience of spontaneity and lightness, all in the presence of a lower level of worry than is normally the case. In addition, they feel reassured and have no need to rush. They feel completely relieved in a given situation, believing that everything is fine and they have hope and confidence in the future (subcategory: *Hope*). The borders of one's own limitations become blurred as people experience more possibilities and freedom in their own functioning. This kind of experience is also expressed on a physical and cognitive level. They describe a less intense pain, the absence of burdensome thoughts, and inner calm (subcategory: *Sense of inner peace*).

Note: The category of *Experiencing freedom* subtly connects to other categories, but in relation and comparison to other categories, such as *Experiencing relief*, it differs in intensity. The current parent category connects its subcategories in a different way. The examples may be somewhat less clearly related to the category, as the subtlety of the class makes it difficult to cite literal instances. Namely, the category is more clearly evident from the context or in connection to the participants' experiences.

U1-4: *As if a person can breathe more easily. As if the thoughts are relaxing. I do not know. The body is definitely lighter and free of the pains. The positive thread is woven forward all the time. A kind of positivity, like a clearer, nicer look ahead, I don’t know how to say this.*

U1-4: *Confidence in the future, self-confidence, maybe. If you don’t trust yourself you can’t even trust the future and look forward.*

U1-4: *Difficult things, difficult thoughts. Burdens. Just like one would say to oneself, “It’s not that bad, all will be fine.” Just like a peel falling off.*

Category: Connection with the environment

Connection with the environment is a category that describes a more intense experience of connectedness both at the social level and that with nature. It includes the wider living space, environment, and people. The participants describe a cyclical relationship with the environment, which they perceive as something utterly beautiful and pleasant, while feeling full of energy and experiencing the body as more attuned and lighter at the same time. They describe the surroundings in abstract terms, namely as something "broader" and "magnificent". They feel satisfied and emotionally stable.

U1-4: *[…] later on, this changes to a sort of a width. A kind of feeling that we are really part of the universe, one would say. Especially when the pool is not as busy, when people are not that many, this feeling is even stronger.*

U4-4: *Yeah, especially when the sun is setting and the grass turns gold. This beauty of nature overwhelms me*.

U4-2: *The feeling, because it’s a higher hill, it’s so nice when I climb up to see the view and the surrounding hills. There might even be a bit of fog or clouds. And some animals about. It’s one of those wonderful feelings. It fills you with positive energy in a sense.*

Category: Empowerment

Subcategory: *setting boundaries*

Category *Empowerment* contains the subcategory of *Setting boundaries.* Participating women describe this as feeling personal power in a particular situation and daring to express their desires and beliefs. They were aware of their own importance and value. In addition, they feel the perception of strength on a physical level, which is accompanied by a feeling of relief. They emphasize that they are assertive within relationships, that they stand up for themselves, establish boundaries, as well as protect and unburden themselves (subcategory: *setting boundaries*). There is no direct control present specifically aimed at controlling the situation as this is rather expressed through decisive behaviour.

Note: The category is reflected in participants who have already progressed in the process of dealing with certain situations that previously put them in great distress. The category is rarely seen in the cases and may relate to the fact that the participants were able to turn the initial negative experience in the situation into a positive one, because they knew and dared to react differently than before. The power in question relates to a sense of self-worth. The participants knew how and dared to set boundaries, thus preventing possible exploitation and manipulation, which all served as a defence of their experience and self-evaluation.

U3-3: *I would say so, yes. As a feeling of relief. When I feel the power, I also feel a sort of relief at the same time.*

U3-3: *I feel important to myself, I exist for myself, so I also stand up for myself.*

U5-1: *After the first shock over the words of my father, I changed my mind and said ‘This time, I really haven't done anything wrong.’ I told him in a nice way that I didn’t like the attitude he had towards me. I stood up for myself, which I’d never done before.*

Negative situation

By analyzing 10 micro-phenomenological interviews, we obtained eight categories that represent key factors in the worsening of fibromyalgia symptoms. The following are the categories and subcategories that we obtained based on the research data analysis of key factors that are present in the more intense experiences of the symptoms, around the period when pain and fatigue deepen. The categories identified are: *Lack of social understanding, Low self-esteem, Sense of over-responsibility, Powerlessness, Emotions accompanying physical limitations, Hypersensitivity and perception of reduced physical ability, Inconsistent body perception, and Fibro fog.*

Figure 3

Categories of key factors that aggravate the symptoms of the disease

Categories	Subcategories	Notes
Lack of social understanding	Self-doubt	The category is internally very uniform, so it does not contain a subcategory.
Low self-esteem		Diametrically opposed to the category of *Experiencing oneself (positively)* as a factor of a positive situation. The category is internally very uniform, so it does not contain a subcategory.
Sense of over-responsibility		It represents the diametric opposite of the category of *Experiencing relief* as a factor of a positive situation. The category is internally very uniform, so it does not contain a subcategory.
Powerlessness		The category is internally very uniform, so it does not contain a subcategory.
Emotions accompanying physical limitations		
Hypersensitivity and perception of reduced physical ability	Pain space	
	Experiencing pain	
	Weakness	
	Fatigue	
	Intense body responses	

Inconsistent body perception		As people experience pain in depth, they report a changed sense of ownership. They perceive very painful body parts as not belonging to the body as a whole.
Fibro fog		It represents the diametric opposite of the category of *Focused attention* as a factor of a positive situation.

In the analysis of negative situations, we found more uniform categories, with a smaller number of subcategories than in the analysis of positive situations. With the comparison of factors in a positive and negative situation, we discovered six diametrical categories, namely: *Experiencing one-self (positively) – Low self-esteem*, *Mental clarity – Fibro* fog, and *Experiencing relief – Sense of over-responsibility*.

Category: Lack of social understanding

The category of *Lack of social understanding* (also: feeling misconceived) includes the experience of misunderstanding in social relations. As part of social misunderstanding, participants describe feelings that others do not take them seriously, that they are left to fend for themselves and that they do not receive adequate social support. The presence of this lack of support is expressed by their family members, the health care system, employers, friends, and the extended family. They feel that others do not take them seriously enough. They report that they may have doubts about their own experience and are generally unsure about the reality of pain and other bodily sensations, especially before getting the diagnosis. With the added burden and expectations of other people, the participants feel distressed. In these situations, they also feel unheard and misunderstood, and at the same time want to meet the many expectations of others.

Note: The personality trait of having a desire to please, is more precisely defined through anamnestic data.

U1-1: *Also, at home. Others cannot spot it on you, everyone just expects it. No one takes you seriously. I don’t know, there’s no support from any side, no stimulation.*

U1-1: *Basically, the pain got worse, say, when one severe stress was already behind me. Also, with my small business when things didn’t go the way they should. It was the same with people, when I still had employees. I don't know, communication, relationships.*

U4-1: *This is really difficult, because I don't always know what or rather what situation triggers my uneasiness. But it burdens me the most when I have the feeling that everyone expects something from me and I can't please everyone. Or when I do everything I think others want me to do.*

Category: Low self-esteem

The category of experiencing *Low self-esteem* describes the negatively colored attitudes and feelings towards oneself with which a person directs his actions. People deny the importance of their existence, with the negative emotions directed at them, and their sense of self-importance is reduced. They treat the outer environment as a priority and value it as more important, compared to their inner selves. Low self-esteem has a strong emotional appendage: there are feelings of anger directed at oneself present, disappointment, fear, and self-doubt, which is expressed through concrete thoughts.

U4-1: *There is more anger directed at oneself than disappointment, and there is fear of what will happen next. How will I manage to do everything and in what condition I will be left then?*

U4-3: *Most negative emotions are directed at me.*

U3-3: I do not exist at that moment. *All these emotions are, compared to what happened, nothing. So, at that point, no one will care what I felt, why did it happen, how it happened.*

Category: Sense of over-responsibility

In the category of *Sense of over-responsibility,* there are descriptions of participants about experiencing a sense of over-responsibility and overload. Participating women experience overload mostly on the cognitive level, the feeling of lack of control over the environment, and losing control over themselves. The feeling of overload describes a negative experience caused by rushing and coping with too much workload. They are also accompanied by a physical experience of deep pain. There is a noticeable tendency towards perfectionism, e.g. they set excessively high demands, which they "must" or "have to" successfully meet, otherwise they feel distress. They are extremely critical of themselves.

Note: The category of *Sense of over-responsibility* represents the diametric opposite of the category of *Experiencing relief*, as a factor of a positive situation.

U4-1: *I don't want to 'not do' anything. Because he surely still thinks I have to do everything.*

Note: the example shows a tendency towards perfectionism, which is otherwise more pronounced through anamnestic data.

U1-3: *I felt less in control of my emotions, thoughts, and body.*

U6-4: *Rushing into things always exacerbates the pain. That feeling of being tightened up. You're all tense. With fibromyalgia, the muscles are tightened. There's no real blood circulation and the pain is definitely greater as a result.*

Category: Powerlessness

Within the category of feeling *Powerlessness*, the participants describe the experience that in a given situation they do not have the ability to do anything to improve the uncomfortable state. They experience the situation as if they have no influence in it. Feeling of powerlessness is a concept accompanied by feelings of disappointment, anger, and sadness. At the bodily level, the experience is expressed by a reduced level of energy and overall physical exhaustion. People describe that they feel holistically empty and limited in performance as they are unable to perform activities.

U1-1: *You're like a sort of shell.*

U4-3: I had no more energy, I was completely exhausted. All I could do is sit on the floor. And I cried with disappointment, in anger and all powerless because I knew I had to do something and couldn't just stay on the middle of the hill. I have to do 'something'. Do I go up to the top where I can rest a bit and eat something or do I go back down in the state I am. The worst thing at such a moment is the disappointment you feel with your body. You want to go somewhere, but the body doesn't cooperate.

U4-3: A little before the top, about half an hour away from the summit, I couldn't go on. The body simply did not go. And then that most awful feeling came when I said: 'It's half an hour to the top, an hour back to the bottom, so what now? If I can't get to the top, how do I get back down?' And it was so awful that I sat down on the floor and cried. You have the feeling that you're unable to do anything. As if you were run over by a train you cannot move, you can't think.

Category: Emotions accompanying physical limitations

The category of *Emotions accompanying physical limitations* describes the experience of anger, sadness, disappointment, guilty conscience, anxiety and fear. The perception of emotions also extends to the body level, where it manifests itself as a feeling of physical restlessness, tightness, and tingling sensations. With profound pain, the body perception altered. The participants would like to move away from the uncomfortable experience by "exiting" their bodies. There is a feeling of sadness and disappointment that is directed them primarily at themselves. They feel pressure in their abdomen and head. Anxiety is most often felt on the level of the body as pressure in the chest and a lump-like sensation in the stomach. When frightened, the participants feel uncomfortable tingling sensations and high pressure in their heads.

U4-1: *Anxiety strikes me after being angry. Then I feel it in my teeth and jaw, a feeling similar to having a high fever. I can't describe it. The whole body becomes or rather it feels like you have a high fever. It's not in my head, because I'm not hot, I am not "boiling over". In the body, arms, legs, teeth, the sensations come as if one would startle an ant hill, but it's not purely shivering.*

U4-3: *I'm disappointed that it's so hard for me to do what I set out to do, whatever's nice for me. Why do I have to collapse in the meantime?! Why do I have to go through the crisis?!*

U5-1: *I didn't find the answer, I just wanted to get away. That feeling when you just want to leave from an awkward situation. I felt a tension all over my body, my muscles were cramping, ready to run.*

Category: Hypersensitivity and perception of reduced physical ability

Subcategories: *pain space, experiencing pain, weakness, fatigue, intense body responses*

In the category of *Hypersensitivity and perception of reduced physical ability,* the participants describe intense perception of pain and hypersensitivity, which is related to the body's unpleasant response to external stimuli. The body responds intensely and painfully to stimuli such as noise, touch, or light. The pain and fatigue deepen. The *Experiencing pain* sub-category describes different forms of pain, which can be sharp, dull, burning, punctate, or perceived as a sensation of heaviness and tension. The subcategory *Pain space* covers the whole body. Some pains are stationary, while others are constantly migrating all over the body. Most often, participants described pain in the shoulders, neck, thighs, feet, chest, and head. They try to reduce their problems with differentiating their behaviour and movements. Unexplained *deep fatigue* is highlighted, which they describe as a state of overall exhaustion with their functioning severely limited. The body feels as being under a heavy load, with the lack of energy, stomach nausea, and headaches often reported.

U4-1: *Then the sounds bother me, and if someone asks me something or tells me something. Whatever.*

U6-1: *Leg and hip pain is constant – burning pain along the entire length. It comes from the inside and radiates all over the skin.*

U5-3: *Like turning the switch, turning me "off". Moving from that severe stress to a sudden shut down. That happened when my boyfriend put me together and I already saw the solution.*

Category: Inconsistent body awareness

The symptoms of both pain and fatigue are deduced through the perception of the participants' bodies. In this category participants describe the various changes in perception, ranging from no clear perception of forms within a section of the body, to the sense of altered ownership of their body parts. Descriptions of body perception vary between participants. Certain parts are not perceived at all, while other parts of the body are expressed clearly. Differences are also reflected within the holistic perception of the body. Some participants pay attention to the whole body, while others only mind and notice the painful elements of the body. The category describes a differentiating or rather inconsistent perception or awareness of the body.

Note: With exacerbated pain, the perception of the participants' bodies changes. With individuals experiencing severe aggravation of the symptoms, it seems that certain parts of the body do not belong to the body as a whole. There have been only a handful of cases among the data obtained, but we find them relevant for investigating the embodied experience of pain.

U1-3: *Inside one hand, I don’t feel shapes very clearly, but fingers are very clearly separated from each other.*

U6 -1: *I perceive my body as a whole. I pay attention only to the pain, which has really increased significantly for me.*

U4-1: *The legs become soft, or they become heavy, as if experiencing the pins-and-needles, as if they weren’t quite my feet.*

Category: Fibro fog

The category *Fibro fog* describes a reduced functionality of cognitive abilities, where the participants are unable to collect their thoughts and maintain a clear mental flow. They mention memory problems, decreased ability of quick and effective thinking, and difficulty redirecting concentration. The planning process is difficult or even impossible. The way of dealing with the described problems differs among the participants. If they are forced to face any situation in a state of experiencing fibro fog, they must use their entire concentration for the purpose of exercising a given task. In doing so, they use the full capacity of their powers that are still available to them.

Note: The category of *Fibro fog* represents the diametric opposite to the category of *Mental clarity* as a factor of a positive situation.

U4-1: *I don't know. My head is empty and full at the same time. It is devoid of clear thoughts and yet full of some unpleasant thoughts that I find hard to discern.*

U1-1: *It’s kind of like your head stopping you. It doesn't let you function. Planning is difficult.*

U4-3: *I need to have a lot of control over my body to somehow get over the feeling. I have to think about every step and move in order to carry it out. You don't think about anything else, as I have to focus 100% of my attention on the task at hand.*

3.2 CODEBOOK 2

The fibromyalgia experience reported by the participants involves the process, all the way from the onset of the initial mildly pronounced symptoms, to the search for a diagnosis, and the subsequent establishment of coping strategies for mitigating the syndrome after the diagnosis has been made.

Based on the experimental theory, we discovered a diachronic model that represents the process of development of fibromyalgia symptoms. It includes three consecutive process periods: firstly, the *Onset of fibromyalgia symptoms*, secondly, the *Aggravation of fibromyalgia symptoms*, and thirdly, *Coping with fibromyalgia symptoms*. The categories included in the period of the *Onset of fibromyalgia symptoms* are the following: *Onset of first symptoms*, *Limited functioning,* the *Experience and awareness of the body*, and *Functioning in overload*. This is followed by a period of *Aggravation of fibromyalgia symptoms,* which contains the categories: *Experiencing symptoms before diagnosis*, *Unpleasant emotion prior to diagnosis*, *Gradually impaired functioning*, and the *Importance of diagnosis*. In the third period, which covers the period set by the clinical diagnosis, namely *Coping with fibromyalgia symptoms,* describes the categories of *Learning physical awareness*, *Fluctuation in functioning*, *Giving meaning to the pain*, and *Changing the form and experience of pain*. Some categories do not contain subcategories, as they are uniform enough as it is and further disambiguation was not deemed necessary.

Figure 4

Categories of experiencing the symptoms

Process period	Category	Subcategory	Notes
Onset of fibromyalgia symptoms	Onset of first symptoms	Emergence of pain and fatigue	
		Abnormal body response	
	Limited functioning	Difficulty functioning in social relations	
		Daily workload	
	Lack of body awareness		The category is internally uniform, so

			it does not contain a subcategory.
	Functioning in overload		The category is internally uniform, so it does not contain a subcategory.
Aggravation of fibromyalgia symptoms	Experiencing symptoms before diagnosis	Forms and migration of pain	
		Overall exhaustion	
		Limitations in functioning	
	Unpleasant emotions prior to diagnosis	Experiencing fear	
		Feeling lack of support	
	Gradually impaired functioning		The category is internally uniform, so it does not contain a subcategory.
	Importance of the diagnosis		The category is internally uniform, so it does not contain a subcategory.
Coping with fibromyalgia symptoms	Learning physical awareness		The category is internally uniform, so it does not contain a subcategory.
	Fluctuations in functioning		The category is internally uniform, so it does not contain a subcategory.
	Giving meaning to the pain		The category is internally uniform, so it does not contain a subcategory.
	Changing the form and experience of pain		The category is internally uniform, so it does not contain a subcategory.

Period: Onset of Fibromyalgia Symptoms

Category: The Onset of First Symptoms

Subcategory: *first symptoms*, and *abnormal body response*

The *first symptoms* that appeared varied among the participants. In most of the cases, the development of symptoms began with the onset of new and previously unknown pain, all of which appeared seemingly ‘spontaneously’, without previous physical injuries and defects. The symptoms also appeared after a case of pulmonary embolism, and in another case, after an accident. The exact localization of the pain was not possible as the pain was constantly migrating throughout the body. In a minority of participants, however, the symptoms appeared primarily in the form of overall fatigue and personal perception of malaise, which visibly hindered their functioning. In addition to pain and overall fatigue, two of the participants experienced a previously unknown body response, for example, in the form of an allergic reaction. The consequences of the allergic reaction were long-lasting, and general well-being was significantly reduced as a result. This reaction is described as a tipping point in the onset of reduced energy levels of the patient.

U3: *Two years ago, severe burning pain in the joints all over the body appeared. The burning pain has migrated and still moves throughout the body, it is present in a certain area for a week or two and then moves to another part of the body.*

U6: *I felt pain everywhere, I couldn’t even define where it hurt me. Just about everything hurt me. They [pains] started in 2009, about a year after I recovered from a pulmonary embolism. A few months after the pulmonary embolism, my legs and hips began to ache. So, I was using crutches for 3 months. After a few months, I started to notice that everything was beginning to hurt me. The pain was severe. I don’t remember which pain was the worst.*

U1: *10 years ago, for the first time in my life, I had an [allergic] reaction all over my body, a severe itching. I don’t know what I was allergic to. I went to the doctor. My whole body and face itched. It started on the legs and went up the body, lasting for 10 days. There were small bumps. I haven’t felt well since. There was a general discomfort present, a kind of lethargy.*

Category: Limited Functioning

Subcategories: *difficulty functioning in social relations*, and *daily workload*

The category of *Limited functioning* contains subcategories of *Difficulty functioning in social relations* and *Daily workload.* As part of the subcategory of *Daily workload,* the functioning and experience of the participants before the clinical diagnosis is described. Often, the individuals were exposed to a number of workloads that occupied their functioning. The women took care of the family and were very active at work. Participants describe that they were doing several jobs simultaneously at the same time or were responsible for their own company.

The subcategory shows the manner in which participants function in social relations, and some other personal characteristics. In interpersonal relationships, individuals tend to please the desires and expectations of others. They often adapt and express their own beliefs and desires inadequately. In case of greater assertiveness, they feel a guilty conscience and doubt. They describe that they are very susceptible to bad relationships and often take responsibility, even if they are aware that they are in no way responsible for any wrongdoing. In interpersonal relationships, they express greater criticism of themselves and are at the same time less critical of others. In a situation where they do not meet the needs of other people they feel distressed. They otherwise do their jobs efficiently and responsibly, which is also evident in the work environment that they occupy. Furthermore, they also complete the tasks that are not a part of their formal work requirements, and consequently take on too much responsibility for other people. The participants are responsible, working people with a desire for structure and efficient work.

U2: *I had two jobs for 26 years. Before retiring due to my disabilities, I had more and more jobs at the same time. I worked 16 hours a day on average.*

U2: *Everything had to be structured up-to-date, to do as much as possible. There was no other way.*

U1: *I was always susceptible to bad relationships, I immediately knew if there were any bad relationships around. In the salon or at home, I felt something was going on. It didn't matter if the bad relationships were tied to me or not, but I always had a bad feeling, that I was to blame, even though this wasn't the case. I always had a guilty conscience. Even when I had employees, I always had a guilty conscience, what if I didn't do or say something well…*

Category: Lack of Body Awareness

In the category of *Lack of body awareness* that occurs before the diagnosis, participants did not pay attention to physical experience during the early development of the syndrome. Absence of physical awareness prevailed. Pains were present, but their perception was present to a reduced extent. Even under heavy burdens, the individual did not perceive what was happening in their body. It was only with the onset of more intense pains that the individuals gradually became aware of the uncomfortable processes in the body.

U1: *Three completely different jobs. Sometimes up to 4 days without sleep. I did this for 3 years. In 2008 I closed my freelance business. I worked three jobs from 2005 to 2007. At the time, I was like a bulldozer, not even aware of my body. I suffered mainly because of the* *financial difficulties which kept piling up. There was always something I had to deal with. It was hard.*

U2: *I wish I could see the changes in my life sooner. I should have listened to my pain sooner. And not wait all these years. I waited for too long.*

U6: *I wasn't paying attention to my other problems. Other than everything hurting all the time, it was what it was. I didn't deal with it at all anymore. I didn't even want to nag anyone. It didn't matter to me.*

Category: Functioning in overload

Despite the onset of pain and fatigue, participants report that they have not adapted their lifestyle to the limited abilities. The *Functioning in overload* category describes the participants' overloaded daily routine. Despite the distress, pain, and fatigue, their way of coping with such a congested workload is based on putting extra effort into their work. Previous behavioural patterns, a sense of over-responsibility, and internalised expectations prevented them from adjusting the way they functioned, e.g. by reducing the amount of the workload.

U1: *In the beginning, I still managed to do everything, but with difficulty. I was so exhausted. I couldn't take it anymore. I still did everything.*

U3: *As a person I was lively, sociable, I liked to laugh, I was hyperactive, now I am slow more and more often. In my life, I was always agreeable, I tried to do as much as possible, I was always in a hurry and thinking about what I urgently needed to do. I recognize that I have often gone beyond my limits.*

U5: *I've always been so focused that despite the pain, I always managed to do everything. Somehow, I always came to the end. I was self-employed and worked as a seamstress.*

Period: Aggravation of Fibromyalgia Symptoms

Category: Experiencing symptoms before diagnosis

Subcategories: *forms and migration of pain*, *overall exhaustion*, and *limitations in functioning*

The pain experienced varied between the participating women in form and according to the area of pain. The subcategory of *Forms and migration of pain* found the presence of pain throughout the body, with highlighted pain areas along the legs all the way to the knees, neck, head, and back. The pain reached to the very depths of the body, namely muscles or bones. The pain began to develop gradually and escalated in intensity over time. Participants describe the presence of punctate, sharp, and burning pain. The pain area occupied the entire body as the pain moved throughout the body and limited normal functioning, which could be seen in frequent sick leaves taken from work. They were forced to adjust their daily activities, body movements and behaviour. Severe pain was accompanied by a feeling of fear and powerlessness. The pain also affected the participants' quality of sleep. At night, the discomfort woke them up and shortened their sleep cycle.

Deepened fatigue or feelings of overall exhaustion are strong factors that reduce the quality of life. People can no longer cope with daily tasks in the same way as they were able to before the two symptoms appeared. The subcategory of *Overall exhaustion* describes a state of profound exhaustion that can be interpreted with the metaphor *"as if you were run over by a train"*. Life gets tough, the clash with the daily challenges gets more difficult and some are no longer able to perform altogether. Feeling sick or exhausted forced the individuals to move away from social interactions. Often, they are further accompanied by strong emotions of disappointment, fear, anger, and sadness.

U2: *Before the burning sensations came, there was pain present like someone had stabbed me in the lower back with a sewing needle, twist it and try and find the most painful position. Every time the pain arrived, it was directed to a specific spot and ever deeper inside.*

U1: *When my feet started to hurt, it was awful. I couldn't even stand on my feet in the morning. I just sat on the bed. To get to the living room I had to cling to the walls. I just couldn't stand on my feet, the pain was that bad.*

U4: *The fatigue troubling me was so intense that I had to lock myself in the bedroom, put the blinds down, and turn off the radio. And no one was allowed near, so that after a couple of hours I came to my senses and could function again somewhat.*

Category: Unpleasant emotions prior to the diagnosis

Subcategories: e*xperiencing fear* and *feeling a lack of support*

The category presenting *Unpleasant emotions prior to diagnosis* includes descriptions of the subcategories *Experiencing fear,* and *Feeling a lack of support.* Within the scope of fear, we discuss experiencing anxiety, fear, and powerlessness about the unknown states of the body. The persons were in distress as they did not understand the processes and changes in the body. There was fear of lurking danger present. When seeking help, the women often encountered an absence of support in the professional sphere, as well as lack of help from relatives and friends. They were frequently forced to prove and explain their ill condition. Participants were faced with doubts in their own experience of well-being, felt lonely, and disappointed. Medical institutions treated them inappropriately and with visible stigma.

U1: *The fear only got worse. In the beginning, I welcomed it all with open arms, in the sense "it will be fine". Then the problems just kept piling up, there was always something amiss. It really wasn't about fearing for my health or that something terrible would happen. I feared being powerless. I was afraid to go for a hike in the hills. I was afraid of diving, in case I couldn't get out of the water.*

U2: *I was alone in this whole process, 75% alone. Every now and then you had someone to complain to and tell him something.*

U5: *No kind of physiotherapy helped me, no medication. Nothing. To my physician, however, I was a hypochondriac. Then I changed my doctor.*

Category: Gradually impaired functioning

The deterioration of well-being and the state of general dysfunction develop gradually. The participants changed their way of functioning only after intense symptoms emerged, namely when the pain and/or fatigue deepened, with fear appearing soon after. Deterioration ensued as a response to intense stress. The process is often attributed to the prolonged overload of the day-to-day functioning. The participants did not respond to inner calls of the body that appeared as initial symptoms. As the intensity of the pain increased, the they were forced to adjust their lifestyle, as they were no longer capable of "normal" operation or were unable to function in a way that they were previously accustomed to.

U1: *When my father died at the end of 2013, I was completely drained, the fatigue deepened with death, and the only power I had left I spent on visiting the cemetery. I worked normally. But the feeling only got worse. Every day was just like that, with no major improvements.*

U2: *I started working on myself when I was no longer able to function as I used to. Much too late. By then [the problem] was already there. The agony was so bad that you woke up in greater pain than the one you went to bed with in the evening. You couldn't sleep or do anything.*

U5: *The deterioration started in 2017, that's when we started building the house. It brought along a lot of problems and financial costs. That same year, my little two-year-old grandson experienced severe epileptic seizures, up to seven a day. He had to re-learn to walk and all, his muscles were gone. My condition worsened, not immediately, but as soon as the situation calmed down. Somehow, I couldn't put myself back together.*

Category: Importance of the diagnosis

The establishment of the diagnosis was an important factor for the participants. They describe feelings of relief and resolution to the processes of trying to find the answers to their questions. The information about one's own state of health enabled the individuals to find new and effective remedies, start the process of acceptance, and reduce the intensity of fear. They felt as if being allowed to calm down and gradually adjust their lifestyle to their needs and abilities. With the diagnosis, the participants were given confirmation that something was legitimately wrong with them and that the malaise was not a figment of their imagination or the result of other exterior reasons.

U1: *I was diagnosed with fibromyalgia in 2017. That's when I stopped myself.*

U2: *To me, the diagnosis represented the conclusion of the process, a relief. I was able to talk to someone about it – what it actually is and asking is there anything else I can do to help myself. They taught me how to live with it, and how I can ease the way I function.*

U5: *Ever since I've been diagnosed, I have felt a sort of a resolution. A clear message that I have not been a hypochondriac for years and years. At the doctors, they treated me as if I was pretending that everything hurt me. Whatever examination I underwent, not a single one showed anything wrong with me.*

Period: Coping with symptoms

Category: Learning body awareness

The third process period represents the span of *Coping with the symptoms* of fibromyalgia after a previously established diagnosis. In the category of *Learning body awareness*, there are descriptions provided by the participants about the way they direct greater focus on the perception of their own bodies. The participants became consciously more attentive to physical signs, as this was the only way they could adjust their behaviour and try to regulate the symptoms. This type of learning is part of the official medical proceedings, namely within the framework of making the clinical diagnosis, and an essential part of the therapies that follow.

U2: *Even with a hunch, you can feel that there's something present, that you mustn't do it no more. There's a kind of pressure, a warning signal, like a needle that stings and spikes. A warning sign.*

U6: *I'm still learning to connect everything that leads to deterioration. I try, I learn. It was only after visiting the Soča Rehabilitation Institute that I began to pay attention to it. I haven't been paying attention before at all.*

U4: *Over time, you somehow learn to ignore it all. You learn to ignore the pain and fatigue. I haven't learned to ignore the stress yet. But whatever's happening to you, you learn and know it will pass in half an hour or two. And you try to go past it, like it's happening to someone else. You're waiting for it to pass.*

Category: Fluctuations in functioning

In their way of functioning, the participating women still find themselves in situations where they overload their own capacities and hinder the socializing aspect. Despite constant efforts to cope with fibromyalgia, they find themselves in old behavioral and thought patterns. In the instances when people find themselves “following the same old tracks” of functioning, physical and cognitive abilities are reduced. Pain and fatigue worsen, and mental oversaturation ensues, usually accompanied by low mood.

U1: *The belief that I do nothing is still present. I still cannot see all the things clearly.*

U3: *Sometimes I switch off completely. Someone’s telling me something, but I stop following, and don’t know what they said. Typically, my concentration is fine in the morning and after 2pm I no longer function. I haven’t noticed any problems with my memory. The condition affects a limited part of my daily functioning.*

U4: *I used to and still have a guilty conscience about my tasks not being solved good enough. It affects my well-being immensely. It’s hard to accept that you cannot do everything. Because I want to do more.*

Category: Giving meaning to the pain

Participants describe experiencing pain as something constant, that is, present all the time. The space in which pain operates encompasses the body as a whole, with the pain migrating throughout the body and varying in the articulation of intensity. Experiencing such pain has a major impact on coping with daily activities and commitments. After the diagnosis is set, the experience of pain changes, namely that the afflicted subjects understand it and attribute it to the diagnosis.

U2: *The worst pain was in the spine, only in the middle of it, the vertebrae, from the neck to the lower back.*

U4: *The pain is present almost all the time, but it is not as annoying. It is moving.*

U6: *The leg is especially difficult; the pain is present all the time. It is usually very piercing.*

Category: Changing the form and experience of pain

With personal problems and misunderstandings, the symptoms deepen. In the category of *Changing the form and experience of pain*, the women participating in the research described a distinctive and otherwise altered experience of pain. The form of the pain turns into a burning one and the exhaustion also deepens. The severity of pain advances in the presence of negative stress. In addition to the transformation of pain, people also describe experiencing disappointment and doubt in moments of distress. Even with positively marked stress, the symptoms mutate, but in a slightly different way. Above all, the fatigue deepens, while having a lesser effect on the experience of pain.

U2: *After visiting Valdoltra and Šempeter hospitals, the pains intensified when other problems arose. Then came the intense burning inflammatory pain that makes you realize that you can no longer sustain your way of life. When you see what's going on, and that you have no understanding of it. That you have no-one to help you, that you're left to your own devices. Then this turns into another pain.*

U4: *I am most upset because my symptoms worsen even under positive stress. For example, when I'm looking forward to something, something beautiful waiting for me, I'm completely devastated about it. This is burdening me the most.*

U6: *With positive stress, I feel my fatigue getting deeper. With the negative one, however, the pain greatly increases. My whole body hurts.*

How do people with fibromyalgia cope with the disease?

When asked how individuals cope with the disease, we focused on the behavioral level of functioning of the participants. The categories we formed were included in the process period of *Aggravation of fibromyalgia symptoms* and *Coping with the symptoms.* Adjustments and alterations in functioning occur only at the stage when the symptoms have already visibly deepened, so the period of the onset of symptoms is not included, as is the case with the question of symptomatology experience. The categories are formed and divided into: *Treatment prior to diagnosis, Treatment post diagnosis, Difficulty coping with daily life* and *Searching for balance.*

Figure 5

Categories of coping with the symptoms of fibromyalgia syndrome

Period	Category	Subcategory	Notes
Aggravation of fibromyalgia symptoms	Treatment prior to diagnosis		The category is internally uniform, so it does not contain a subcategory.
	Treatment post diagnosis		The category is internally uniform, so it does not contain a subcategory.
Coping with the symptoms	Difficulty coping with daily life		The category is internally uniform, so

			it does not contain a subcategory.
	Searching for balance	Awareness	
		Dietary change	
		Regular exercise	
		Sense of support	
		Setting boundaries in relationships	

Period: Aggravation of Fibromyalgia Symptoms

Category: Treatment prior to diagnosis

As part of the medical treatments, the participants looked for answers to the problems caused by the symptoms of the syndrome. They describe a plethora of medical and diagnostic examinations, namely psychological, psychiatric, and rheumatological treatment, an ultrasound examination, a visit to the family doctor, an orthopaedic examination, and a treatment at the University Rehabilitation Center Soča, etc. The time span from the onset of first symptoms to the clinical diagnosis varies between participants. Four out of six participants were involved in a lengthy process of finding a diagnosis that lasted for multiple years.

U2: *And then I had all kinds of different consultations, with different experts. No one tells you anything, meanwhile, I was afraid to move because it hurt so badly. You don't know what to do, how to help yourself. You can't function on your back, nor on your hips and abdomen. It just hurts.*

U1: *The doctor then referred me to a rheumatologist because I was telling her about all of the joint pain. While waiting for an appointment with the rheumatologist, I underwent various examinations, all results were deemed 'unremarkable', so they referred me to a psychiatrist. I said I would go to the moon and back, just to get a diagnosis. Then I started visiting a psychiatrist, later on, also a rheumatologist, and they diagnosed me with fibromyalgia. Then I got a referral for the Soča Institute.*

U4: *At the time, I was sent on a number of examinations. On an ultrasound exam of the heart, and another embolism examination. Every possible one. All the results were fine, 'unremarkable'.*

Category: Treatment post diagnosis

The treatment process after the clinical diagnosis varied between participants, depending on the needs required by the symptomatology. Category *Treatment post diagnosis* describes a medical treatment involving clinical-psychology, physiotherapy, psychiatric, pharmacological treatment (with Cymbalta, Sanvall and Lyrica), and therapy at the Soča Rehabilitation Institute, which was attended by four of the six participants. Three of the six participants reported not taking the medication prescribed. They manage the symptoms by adjusting their lifestyle.

U1: *In 2017 I got Cymbalta, it helped me be calmer and I no longer had a thousand thoughts in my head. Then I've also taken Lyrica and thank god my leg pain subsided and they became less restless.*

U2: *Formal treatment: Soča Institute, psychological and psychiatric treatment, physiotherapy. I exercise twice a week.*

U4: *I don't take medication, maybe a Brufen here and there, if it's severe.*

Period: Coping with symptoms

Category: Difficulty coping with daily life

The symptoms forced the women to adapt daily to some mundane and basic tasks, such as dressing up. The pain caused restrictions in movement. Individuals were forced to pay attention to any misaligned movement that could trigger the development of additional pain.

They are often stigmatized by the medical staff due to the diagnosis. Individuals describe that they avoid talking and explaining about the medical condition and diagnosis when interacting with healthcare professionals, as this often results in disappointment. The syndrome represents a great challenge and additional burden on their careers. Pain and fatigue limit the participants' performance, work efficiency, and consequently increases the amount of sick leave. They are often even obliged into taking the sick leave from work.

U5: *In the morning, when I'm most clumsy, I aid myself by preparing a pile of clothes to wear when I go to the bathroom, and as I'm already sitting down I also get dressed so I don't need to bend down and squat again. This way I don't have to squat and stand up too many times. It was awful standing up from a squat. I felt so much pain.*

U2: *It was difficult. I've learned to avoid and not say what's troubling me. People don't understand.*

U3: *I am on sick leave several times a month, so I only work for half a month or less on average. The longest sick leave lasted for three months.*

Category: Searching for balance

Subcategories: *awareness*, *dietary change*, *regular exercise*, *sense of support*, and *setting boundaries in relationships*

The *Search for balance* category includes the subcategories of *Awareness*, *Dietary changes, Regular exercise, Sense of support*, and *Setting boundaries in relationships*. With fibromyalgia, it is crucial to identify and establish behavioural strategies, with a direct goal to regulate the symptomatology of the syndrome. The women in this research reported that in order to effectively confront the issue at hand, they had to focus their attention to the body and body-awareness. A more directed attention to the realm of the physical, enables simpler regulation of their behaviour for the purposes of preventing the reappearance of severe pain and other symptoms. Within the subcategory of *Dietary change,* the importance of diet is described, namely as a key mechanism in curbing inflammatory reactions in the body, and as a means of reducing sensitivity to pain in the aching muscle fibres. Lowering the intake of sugar and fat helped them lose the extra pounds, while also raising the level of their general well-being.

The next subcategory of *Regular exercise* is based on descriptions of the positive effects physical activity had on the participants. As people gradually build their muscle mass and increase their general level of fitness, their productivity levels and general well-being increase. Individuals battling the syndrome are often slightly less involved in social life. They describe that by engaging in social interactions, they have gained a *Sense of support* and acceptance. Establishing social support helps to reduce one's fears and brings about a sense of belonging. Through pleasant interactions, the individuals are more attentive of themselves and their experience. In relationships, they learn to *Set personal boundaries,* which are crucial for building quality relationships and maintaining psychophysical health.

U1: *When I wrote in my diaries, I could finally see what I'm doing. I didn't even realize how much I was working before. Now I believe that's exactly when the bad self-image comes out.*

U4: *I changed my diet, I don't eat sugar anymore, I lost weight as a result. This also helped me a great deal to feel better and be able to move more easily.*

U2: *In relationships, I stand up for myself and saying 'no' is no longer difficult for me. No longer hard. And then the days come when you really need the help and you just don't get it, that's when you feel that burning pain.*

3.3 CATEGORIES OF BODY MAPPING TECHNIQUE ANALYSIS

Figure 6

Categories of body mapping technique for the positive and negative experience

Categories	Subcategories	Second order subcategory
Symbolism of the image	Lines	Circular
		Sharp
	Color shades	Bright
		Dark
Spatial arrangement of the image	Holistic body perception	
	Differentiation of body parts	
Associative significance presence in the present	Connection with the environment	
	Connection with others	
	Connection with the body	
	Lightness of body	
	Sense of freedom	
	Blurring of body boundaries	
	Changed perception of ownership	
	Dissociation	
	Emotional state	Joy, happiness
		Anger, fear, disappointment

Note on figure contents: The table highlights the most representative elements of embodied experiences in extremely pleasant and unpleasant situations. The second-order subcategory elements from the positive situations are underlined, the non-marked elements belong to the negative situations.

With the body mapping technique, we wanted to study embodied experiences and their significance for the individual. We were mainly interested in the physical experience of pain and other symptoms and moments where the symptoms were expressed in a lower intensity or were completely absent. We created categories and subcategories for the positive and negative situations together, as the content is highly correlated. There were differences present in the subcategories of the second order, where we divided the elements between different qualities of experience. We designed the categories on three levels, namely: *the symbolism of the image*, *the spatial distribution*, and the *associative meaning of the image*. The category of *image symbolism* includes collected elements that have a significant meaning of the experience for the participant. At the level of image symbolism, we created subcategories of *lines* and *colour shades*.

The lines of the negative course of the experience are presented more sharply and show the space of intense pain. Different forms of pain are shown with different representations. Stabbing pain is shown in the form of dots or shorter sharp lines that indicate a narrower and more specific pain space. The sharp edges of the representations of the images show, above all, high intensity pain. Rough patterns with dark colour shades (blue, black, green) are shown, with no delicate motifs in the areas that clearly symbolize physical problems. Burning pain is symbolized with the colour red. Arrows represent the spreading and moving of the pain space.

Through the positive course of the experience elements are shaped with softer and circular lines. Blunt angles with fluid transitions and mild contrasts between the body and the environment predominate, reminiscent of a pleasant interaction between the body and the wider environment. Experiencing the body acts as part of a larger whole. Participants often used light shades of colours, such as yellow, light blue, light green, orange, and pink. With gentle lines and symbols, such as hearts, clouds and bright shades of colours, the participants graphically depict the lightness and softness from the described experienced positive situation.

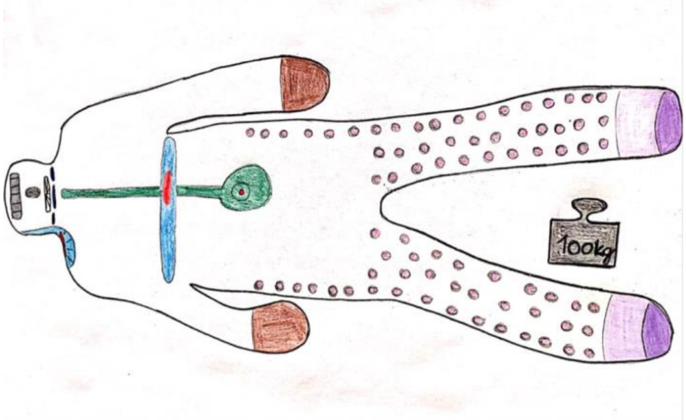
The subcategories for the category of spatial distribution were named *holistic perception of the body* and *differentiation of body parts*. In a positive experience, the images are shown to be less differentiated within the body. The contouring of the whole body with circular lines and warm colours predominates, which indicates the relaxation and unity of the body. The body is portrayed as floating. Within the body, certain areas are emphasized, which especially stand out with the experience of relaxation and lightness. Most often, the participants emphasized the chest, head, and legs. In the negative experience, the participants differentiated their body into many painful areas. In moments of extreme and severe pain, the images are almost empty. the body is outlined, only a certain pain space is emphasized, which stands out in intensity. Pain is too stressful for participants to cognitively incorporate into their experience. The focus is on the participant herself; the perception of the body is extremely limited. The image is bare, with only a few elements added to the whole depiction. In the case of body differentiation, different forms of pain are shown, at different pain locations. As a result, the body image is richer. The pain areas that are most often highlighted are the legs, arms, head, and chest.

Within the category of *associative significance of the image*, symbolic representations of complex experiences are represented. Concrete experiences are manifested through abstract images. In rare cases of positive experience, boundaries between body and environment are blurred through the overflow and warm colours from the body out. It represents a merger of boundaries between the body and surrounding. Participants feel accepted.

Emotional experience was rarely clearly represented in body map images. In positive events, it is mainly shown by the symbols of sun and heart, which signify joy and happiness. However, emotions in negative experiences could only be recognised together with the descriptions in the image development process. Anger is displayed in the head, while anxiety, fear, disappointment, and feelings of guilt are depicted in the chest and stomach. With using different images, different emotions are exposed. For example, participants repeatedly drew a rounded shape in the stomach, a “lump” in the abdomen or chest that marks anxiety or fear.

Figure 7

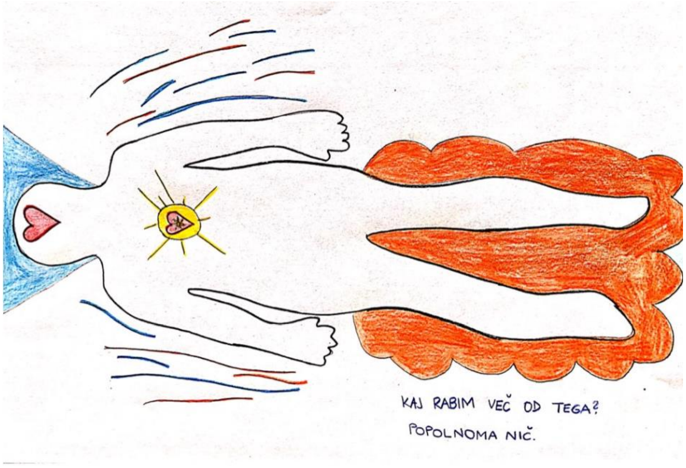
Body map from a negative experience



Notes: According to the key summaries of the participant's description of the image, the dots on the legs symbolize a punctate pain that spills from a smaller into a larger space. The limbs are relatively uniformly coloured and show dull pain. The experience of disappointment is shown in the stomach. The head is full of worries and therefore presents difficulties in forming clear thoughts.

Figure 8

Body map in a positive experience



Notes: According to the key summaries of the participant's description of the body map, the legs are strongly perceived as light, so they are shown as surrounded by a "cloud". The head is light, clear thoughts radiate from the head. The heart and sun in the head and chest symbolize the happiness and joy they experienced at a given moment. The circular lines around the body indicate a pleasant relationship with the environment.

3.4 MULTIDIMENSIONAL ASSESSMENT OF INTEROCEPTIVE AWARENESS ANALYSIS

Table 2

Results of the MAIA questionnaire

		U1	U3	U4	U5	U6	AV	SD
Pre-study	noticing	4,5	4,5	3,5	2	3,5	3,6	1,024695
Post study		4,5	3,5	4	3	4	3,8	0,421900
Pre-study	not-distracting	3,3	0,6	2	1,6	3	2,1	1,090871
Post study		3	3	2,5	1,6	3,6	2,74	0,733294
Pre-study	not-worrying	5	1,6	2,6	1,3	3,6	2,82	1,517234
Post study		2	2	3	1,6	3,6	2,44	0,793675
Pre-study	attention regulation	3,1	2,8	2	4,3	2,3	2,9	0,891628
Post study		3,5	3,6	2	4	2,5	3,12	0,808505
Pre-study	emotional awareness	4,5	3,2	4	5	3,8	4,1	0,685565
Post study		5	4	4,5	4,6	4	4,42	0,284746
Pre-study	self-regulation	3,25	3	1,5	5	3,2	3,19	1,242176
Post study		5	3	2	4,7	3,5	3,64	0,983931
Pre-study	body listening	3,3	3,3	2,6	5	3	3,44	0,918150
Post study		3	4	2,6	4	3	3,32	0,617479
Pre-study	trusting	3,6	3,6	3,6	5	2,6	3,68	0,855570
Post study		4	3,3	4	4,6	2,6	3,7	0,750333

Notes: The table presents the results of the MAIA questionnaire, before the survey and after the survey, separately for each participant. Mean values and standard deviations are calculated for each value of the category before and after the survey. Due to the small sample, other statistical components could not be calculated. Therefore, the analysis and interpretation rely on the average value and the standard deviation of the results. The results of participant two (U2) are not included in the table due to premature termination of participation in the study.

The MAIA questionnaire is a multidimensional assessment of interception awareness, with 32 items and eight dimensions. The table shows the results of five participants in the questionnaire. Average values and standard deviations are calculated.

In the category of emotional awareness, participants average values score the highest. This can be seen in the values both before the survey and in the values of the questionnaire after the survey. On average, the values were lowest in the *not-distracting* category (pre-study). Experience reports were relatively consistent among the participants according to the questionnaire categories, with the most significant difference seen in the *not-distracting* category. The highest variability in responses among the participants, was present in the categories of *noticing* (pre-study), *not-distracting* (pre-study), *not-worrying* (pre-study) and *self-regulation* (pre-study). There were significant differences in individual participants, in the values before and after the study, in participant three on the *not-distracting* scale. After the study, the values indicate that the participant's propensity to distract from feelings of pain and discomfort increased.

The comparison of the results of the questionnaire before and after the research, shows changes in categories *not-distracting* and *self-regulation*. The first category describes a lowered need of diverting the attention away from pain, enabling for a quicker realisation and acceptance of it. Within the category of *self-regulation,* even when the participants are overwhelmed, they find inner peace more easily, they can calm down, both physically and mentally, by breathing and more often by focusing on their body with a sense of peace.

In summary, comparing the questionnaire results before and after the survey does not indicate statistically significant deviations.

4 DISCUSSION

In the chapter of Discussion, Grounded Theories 1 and 2 are presented independently, in the framework of which we explain and compare the results of this study with the findings of other researchers. Grounded Theory 1 was formulated based on the research question about the key factors that influence the improvement or aggravation of symptomatology in fibromyalgia patients (codebook 1). Grounded Theory 2 explains the ways of coping and experiencing the symptoms, from the onset to the present moment (codebook 2). The chapter is finalised by a discussion of body awareness, which is predominantly based on data obtained through the technique of body mapping.

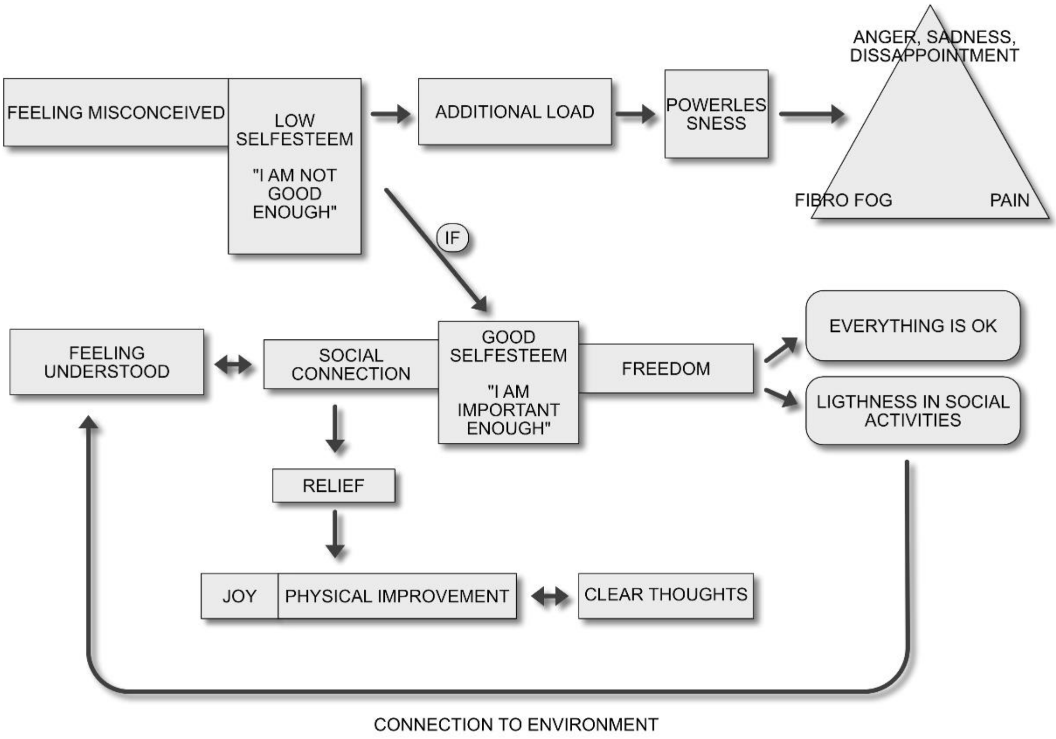
4.1 GROUNDED THEORY 1

With the qualitative analysis of the data, we wanted to investigate the key factors that contribute to the positive and negative experience of symptoms. Based on the data obtained, we designed a grounded theory, which assumes two directions of experience patients with fibromyalgia can be subject to. The first represents the positive experience, in the scope of which people experience less pain, greater physical relaxation, normal energy levels, and easier cognitive functioning. The second direction of experience describes the presence of considerable pain, general malaise, including severe exhaustion, cognition problems, and decreased emotional mood. Functioning on the whole is difficult and limited.

Based on the grounded theory, we designed a diagram. In the schematic descriptions, representative elements of experience, i.e. elements that are present and typical in the experience of all participants, are presented by areas. The experience of each female participant often has additional individual characteristics or elements extrapolated. The grounded theory model is based on the causal and sequential relationship between the listed factors. The diagram shows the sequential process of how the experience of the factors changed in a positive and negative situation. Factors interact in a complex manner, with the changes in experience occurring in short delays, and are difficult to distinguish by time. The arrows represent the time course of the development of the experience and also establish the sequence in which the individual elements of the experience follow each other. The factors that we found to be strongly intertwined, are overlapping or touching in the diagram. With the negative experience, we observe time concurrence on the emotional, cognitive and physical levels, while in the positive processes, more rigid time sequences can be observed.

Figure 9

Diagram of the key factors in a positive and negative experience



A positive course of experience

The designed grounded theory states that the social component is the initial factor that significantly influences the outcome of experiencing the situation and, consequently, the appearance of the symptoms. The model otherwise assumes that a positive development of the experience can be based on two different initial states of social acceptance or perception of one's own placement in the social environment.

The primary development of a positive experience

Insofar as individuals feel understood (code: *understanding*), are connected in a relationship, and are accepted by the environment, which can more widely encompass both the people, animals or nature in general (code: *social connection*), these people feel accepted, unjudged by others, and do not feel the need to please. *"We were connected without having to talk to each other. It was very cute. We looked at each other or helped each other with the drawing* (U6-2)*."* Social acceptance and encouraging circumstances, such as an understanding, accepting, and encouraging environment, affect various aspects of experiencing oneself as *"I am enough"* (code: *self-worth*). People form an awareness of their own importance, existence, they are aware of their abilities and evaluate themselves in a more positive way: "*Strong. I don't know what to say, I feel worth it* (U1-4)*."*

S. J. Waters, et al. (2004) states the importance of the responses of others, which are then internalized into the structure of the 'self' and the shaping of self-experience. In accordance to this notion, our results are based on a similar premise, pointing towards the importance of understanding and accepting social interactions for the effective formation of the 'self', namely, where high self-esteem is formed (*"I am enough"*). The concept of 'self' acts as an integral part of human cognition, motivation, emotionality, and social identity, and helps to maintain one's own sense of basic value. Should the 'self' take a more collectivist perspective, perception is then focused primarily on connections and similarities with others (Oyserman and Markus, 1998). Given the results and the characteristic personality traits of fibromyalgia patients, such as high criticality and a tendency to please (Galvez-Sánchez et al., 2019), we assume that these are the factors that have significantly influenced the formation of self-awareness in participants.

A more pleasant experience of oneself also enables the individuals to accept themselves better and experience relief in the present moment (code: *relief*): "*You aren't burdened with expectations, you don't think you are in debt to someone, should I do this* or that. *This is one of those situations where everything is simple and easy* (U6-4)*."* The need to please and fulfil the expectations of others is reduced. They experience the situation as physically lighter, without any need to rush, and are accompanied by pleasant emotions. The changes are manifested on the physical, cognitive and emotional levels. The areas interact with each other in a complex mode, but we found that the process most likely proceeds sequentially. Pleasant feelings of joy, easing, pleasure and gratitude (code: *joy*) impact and improve physical well-being (code: *physical improvement*): "*Pain in the presence of happiness is notably reduced. All over the body* (U4-2)*."* This is followed by improved cognitive functioning and an increased ability to be present in the experience of the concurrent moment. The flow of thought is clear, fluid, and not oversaturated with thoughts and worries. Participants state that they can control their thought flow (code: *focus of thoughts)*. "*The head is empty. But nicely empty. I am able to follow what is happening. I followed every word that was uttered and every movement of the puppy* (U6-4)*."* As noted by K. W. Brown et al (2007), acceptance of the present moment is associated with non-attachment, feelings of acceptance, and allowing the experience to be as it is. The ability to distance oneself from mental content and trying not to identify with it, as described by R. M. Ryan (2005), reduces the impulsive responses to unpleasant experiences and promotes even greater insight into oneself, others, and one's own humanity. People feel a profound freedom from their own image. The quality of experience we have gained through the analysis is very abstract and difficult to capture verbally. It is not just a matter of relieving expectations of oneself, but it is a matter of a wider freedom of life, which can include a connection to other beings (both humans and animals) and the wider world (code: *experiencing freedom*). *"It's like making it easier for a person to breathe. As if thoughts become relaxed. The body is definitely lighter and free of the pains. Such positive thread is weaves forward all the time. One positivity, a clearer, nicer look ahead, I don't know how to put it* (U1-4)*."*

Relationships are experienced at ease, pleasant, and within them the boundaries set without feelings of guilt. The change of experience is based on the essential belief about the world that everything is fine (code: *everything is OK).* The interaction between the female participants and the world is based on this kind of acceptance present both in subjects within or out of a relationship. Physical well-being is improved, that is, lesser perception of pain, in turn, allows for involvement in simple social activities (code: *lightness in social activities*). V. Compañ et al. (2011) states that inclusion in social life reduces the patients' sense of differentiation from others and increases their sense of belonging, which results in changes of experience and the symptoms. The perception of physical pain changes: *"The relaxed laughter, it was basically really visible that we all got out of the pain. Each in her own way. We were all troubled there. We were somehow very connected after all* (U1-2)*."* The feeling of understanding, acceptance and connection with the environment is further solidified, which includes connectedness with the wider environment, including interpersonal relationships and the relationships with nature and animals (code: *connection with the environment*): *"The feeling comes because it's a higher hill. It's so nice when I climb up to see the view and the surrounding hills. There might even be a bit of fog or clouds. And some animals. It's one of those wonderful feelings. It fills you with positive energy in a sense* (U4-2)*."* This process acts as a positive feedback loop of the experience.
People seem to need external confirmation for a positive self-evaluation in the form of a sense of being accepted, understood, and being part of the community. When the individuals feel valued and accepted enough, the experience will be associated with a more holistic body awareness and less intensely expressed symptoms of pain, fatigue, and impaired cognitive function. This is also evident from the body mapping images, where the participants portrayed their perception of the body more holistically and indicated being in greater contact with their body. The body is shown as a whole, connecting with the environment via the soft, circular lines. There is mental clarity present, light, and pleasant thoughts that the participants are able to control, all of which is indicated by the cloud symbols and the use of bright colours (e.g. Figure U1-2).

The secondary development of a positive experience

In two cases, the data revealed a different, third process of experience. From the initial phase, which was based on social misunderstanding and non-functional relationships (code: *misconceived*), the subject achieved a positive course of experience through a conscious change in the experience of self-worth and importance from non-stimulating social circumstances (also: cognitive reframing). From the initially negative situation, people knew how to influence the experience in the direction of a positive feeling**,** where they knew and dared to react differently than in the previous situations: *"After the first shock over the words of my father, I changed my mind and said "This time, I really haven't done anything wrong." I told him in a nice way that I didn't like the attitude he had towards me. I stood up for myself, which I'd never done before* (U5-1)*."* Through assertive behaviour, the individuals were able to set boundaries in relationships: *"As soon as he starts blackmailing, I know right away that I will set the boundary* (U3-3)*."* The women perceived a change in the way they experienced their own self-worth and as a result stood up and defended themselves (code: *self-worth*). The alter behaviour turned the process of experience into the general direction of a positive experience.

Cognitive flexibility in responding to new and unexpected states allows one to choose the response most appropriate for a given situation instead of being caught in automatic thought patterns that may not represent the most well-adapted response (Chambers et al., 2009). Accordingly, this study also found similar behavioural instances, where participants, through an alternative response to the situation, influenced a change in experience directed towards a sense of power. Adapted and flexible responses to the environment enable the ability to perceive the situation and one's internal responses with greater clarity and greater freedom in choosing the response (Shapiro et al., 2006). The awareness that the environment will not change, but rather that individuals can influence a change in self-perception, allows them to alternate the way they evaluate themselves. People change their experience of the environment by changing their expectations they harbour about the environment, through setting boundaries, and possibly, by better communicative expression, or moving away from an uncomfortable experience. As a result, they feel personal freedom, and do not feel powerless and trapped. They experience power and control over their own functioning.

Negative course of experience

The next course of experiencing the symptoms manifests itself with the perception of more pronounced pain, overall fatigue, impaired cognitive functioning and decreased emotional mood. Perception of the situation in the initial phase is based on the social component: social misunderstanding, disconnection, and dysfunctional relationships: *"[…] By no one believing*

you. I don't feel good. If she was interested in anything else she would probably have some additional questions. With a nod, I get the feeling that she asked me this only out of being polite and that she is not really that interested in how I feel (U3-1)*."* In the case of unwelcoming circumstances due to the desire for understanding, respect and confirmation, the participants are in greater mental and consequently physical stress. The feeling of helplessness, inconsistency and doubts about experiencing oneself increases (Compañ et al., 2011), which is also in line with our findings. The results show that incorrect relationships, inaudibility when overworked, and loneliness, affect the way people experience and value themselves. There is a notable change in the perception of self-awareness, the situation in which the subject is situated, and the overall functioning of the person. In unsupportive circumstances where people feel misunderstood and unaccepted (*"I'm not good enough"*), the symptoms worsen. These findings are consistent with the research of Freitas et al. (2017), who found that fibromyalgia patients with a low rate of positive social interactions (including insufficient social support and stigmatization) have a greater chance of depression, an aggravated experience of the symptoms, and reduced functionality (Freitas et al., 2017).
Crucially, the negatively tinted social component is associated with the formation of one's own self-experience evaluation, relating to the literature of D. Oyserman and H. R. Markus (1998), where they describe ways of incorporating the contents of others into one's self-structure. The collectivist 'self' is more receptive of connection and is clearly relationship-oriented, so we assume it to be an important factor in shaping self-worth in fibromyalgia patients. Due to the environment's perceived disregard, people form a belief in their own inferiority and non-importance: *"Most negative emotions are directed at me* (U4-3)*."* Self-esteem valuations are formed in the direction of perceiving oneself as "not good enough", uncapable and unimportant. The participants direct unpleasant emotions into themselves, which only confirms the fabricated negative beliefs about themselves.

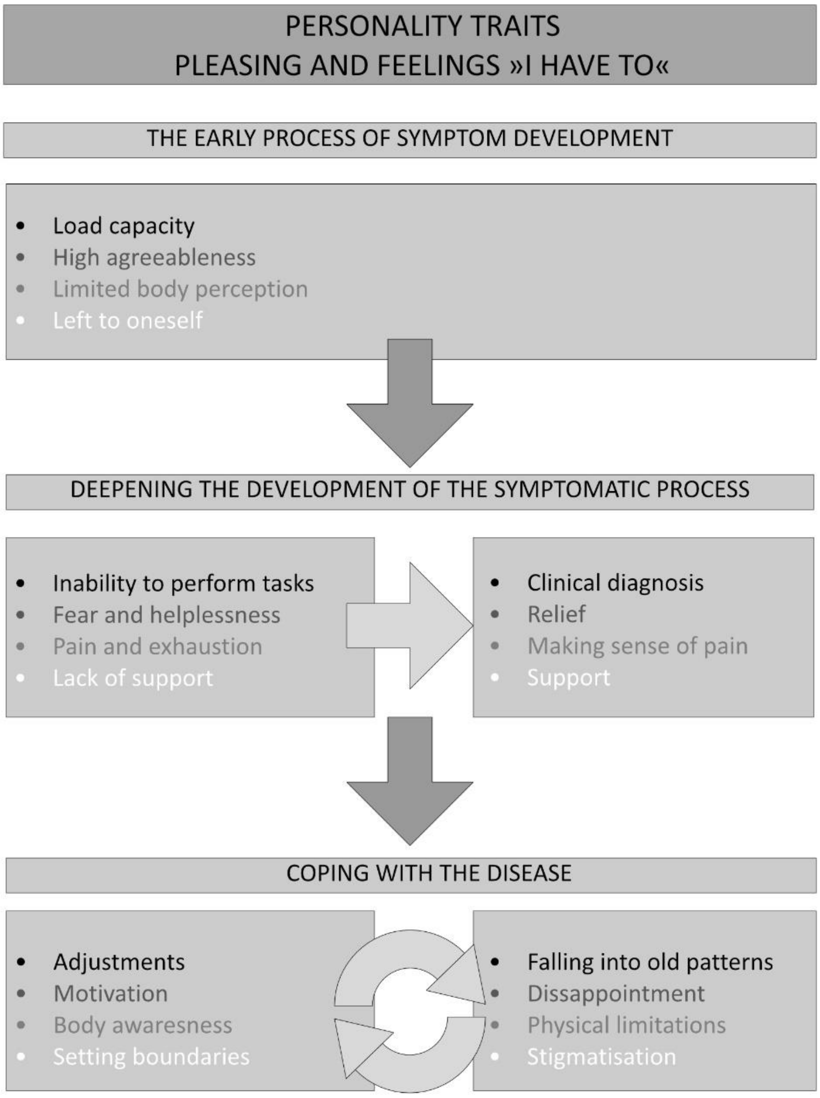
From experiencing *"I am not enough"* (maybe from different aspects), a sense of loneliness, self-indulgence, sense of acceptance of additional burdens and responsibilities, increases (code: *additional burden*). When such a plethora of burdens is not managed adequately, the experience of powerlessness develops (code: *powerlessness*): *"Yes, [I'm] completely helpless. I would also just sit down somewhere and watch everything from afar. I would retract from my life* (U1-3)*."* People feel trapped in the situation and see no way out. Simultaneously, changes in the physical, cognitive and emotional areas ensue. The areas interact and influence each other. The burden affects the mental overload (code: *fibro fog*): *"I just can't. Afterwards I just need some time to myself. I need total peace, I can't think, I can't decide* (U4-1)*."* Effective cognitive functioning, including the ability to plan and direct attention, is difficult for these individuals. Fibro fog is the most representative cognitive element that describes a condition that manifests itself in confusion and difficulty concentrating. The overall sense of body control and one's impact on the environment is unstable. People perceive anger directed at themselves, disappointment, fear and sadness (code: *anger, sadness, disappointment*): *"I'm disappointed that it's so hard for me to do what I set out to do, whatever's nice for me. Why do I have to collapse in the meantime?! Why do I have to go through the crisis?!* (U4-3)*."* At the same time, the symptoms aggravate, the pain, overall exhaustion, and other physical limitations are expressed to a greater extent (code: *pain*): "*Also the nausea. Such fatigue that I'd best just go to sleep. That your skin really hurts, that your whole body hurts immensely* (U1-3)*."*

The process described acts as a negative feedback loop that deepens the experience of the symptoms and distress. The pain experienced, the feeling of heaviness and fatigue were shown graphically by the female participants on the body mapping images. Different parts of the body are exposed, suggesting different forms of pain and other unpleasant bodily experiences such as pins-and-needles tingling, tension, and lack of energy. The head is full of worries and unpleasant emotions. The images produced seem a bit blander and unvivid in comparison to body mapping images of a positive situation.

4.2 GROUNDED THEORY 2

Figure 10

Diagram of the experiential model and coping with the symptoms through the development of fibromyalgia



Notes: Color black indicates experience and coping on a behavioral level. Dark grey describes the experience on an emotional level, light-grey indicates the physical level. In white, experience and confrontation on a social level is listed.

Through the qualitative data analysis, we have created a diachronic model (*Figure 9*), which extrapolates on the trial theory about the different ways individuals confront and experience the symptomatology of the syndrome, all from the onset of first symptoms to the current moment. The model includes three process periods of symptom development: firstly, the period of the early symptom development process, secondly, the deepening of the symptoms, and lastly, the coping with symptomatology. Each process period involves experience and confrontation on four different levels: on emotional *(in dark grey)*, on social *(in white)*, on behavioral *(in black)*, and on physical levels *(in light-grey)*. From two separate research questions, one grounded theory was formed, as the data intertwines, and the two sets significantly complement each other.

Choy and colleagues (2010) state that in addition to experiencing chronic widespread pain as a predominant symptom, the fibromyalgia syndrome also includes general exhaustion, sleep problems, and low concentration, which significantly affect all aspects of human experience (Choy et al., 2010). The latter can also be confirmed by our results, which clearly indicate a changed experience in all areas of functioning. The model assumes that the personality structure significantly influences individuals' responses to stress and may predispose the possibility of developing the syndrome under non-stimulating circumstances, such as excessive stress or improper relationships. Galvez-Sánchez et al., (2019) cites characteristic personality traits that often occur in fibromyalgia patients, such as a tendency to perfectionism, high performance orientation, higher neuroticism, lower self-esteem, and the need for self-evaluation via inspecting one’s competencies and approval of others. The data we collected through the interviews is in concord with the aforementioned theory. In essence, people tend to satisfy the demands and expectations of others, exhibit a high level of responsibility and diligence, express a desire for perfectionism, and show high levels of self-criticism (code: *high agreeableness*): *“I have always given in to my husband. I still do. He says, for example, that he would like to go somewhere, but he doesn’t say where, he just remains quiet. Then the day before or at the very departure, he says, Let’s go elsewhere now, while I have other plans. Whenever he said ‘let’s go there’, I followed him. Like a sheep. I always thought I was weird and that certain things didn’t suit me. But I wasn’t brave enough to express: ‘I just don’t like that’.* (U1)*”* If people cannot comply with the demands, guilty conscience arises: *“I felt guilty when I didn't do enough, if I had to say ‘no’, or if people around me didn't feel good.* (U1)*”*

In the period of early developmental process of the symptoms, individuals operate under high levels of load (code: *load capacity*), which they feel personally responsible for. With loads, they feel left to fend for themselves (code: *left to oneself*). Physical perception is very limited during this period (code: *limited body perception*): *“I don't even remember my body during those burdensome periods. I don't even remember sleeping. I was working three jobs at a time. I was like a bulldozer.* (U1)*”* The attention is not focused on one's own body, but on the surroundings, the workloads and burdens they face. With the aggravation and escalation of the overloaded way of life, the capacities for uninterrupted daily functioning are reduced (code: *inability to perform tasks*). Galvez-Sánchez et al. (2019) cite similar findings of the negative impact of fibromyalgia on the reduction of the physical, mental, and social spheres, as well as on cognitive functioning, personal relationships, work, family care, social roles, and daily tasks. In the process period when symptoms aggravate, pain and general fatigue appear in such intensities that they render functioning more difficult and limited (code: *pain and exhaustion*). *"Burning pain in the thighs and restless legs appeared before the diagnosis. I was awakened by pain every day.* (U2)*"* Individuals have trouble sleeping and difficulty performing daily tasks due to experiencing pain and overall fatigue, which also includes impaired cognitive functioning.

At an unpleasant experience of a situation they are accompanied by a fear of powerlessness and of physical threat due to the lack of understanding of the events happening in their bodies. This also includes the concerns and difficulties in controlling symptoms, scepticism about the diagnosis and distrust of the course of the treatment (code: *fear and helplessness*): *"The fear only got worse. In the beginning, I welcomed it all with open arms, in the sense 'it will be fine'. Then the problems just kept piling up, there was always something amiss. I feared being powerless. I was afraid of not knowing what's going on with me physically, will I be struck by a heart attack, are my lungs are damaged.* (U1)*"* Pain, fatigue, and impaired cognitive function take over and affect self-esteem, interpersonal relationships, and the patient's environment (Galvez-Sánchez et al., 2019). The data show that they feel misunderstood and unaccepted (code: *lack of support*), which affects the increasing feeling of alienation in interpersonal relationships (Galvez-Sánchez et al., 2019).

The perception of the body is directed to the deep pain and overall exhaustion. As the symptoms escalate, loneliness and distress also intensify: *"The heaviest emotional burden was the fact that I was alone. That I had no emotional support at home.* (U2)*"* Due to issues with health, the individuals start seeking medical attention. This is where they encounter many inconveniences: *"Then they sent me for an ultrasound of the heart, for another lung scintigraphy, and to the Golnik Pulmonary Clinic. There I was subtly accused, namely of being a hypochondriac, because I complained about not feeling okay. A very unprofessional attitude.* (U5)*"* A. Gill Taylor et al. (2016) state in their work that the complexity of the disease, the absence of physical injuries and the lack of objective criteria affect the time-consuming process of finding a diagnosis, including numerous visits to health professionals where people experience ignorance of the disease, including the health professionals (Gill Taylor et al., 2016). The results of our study confirm the findings, the time span of the diagnosis varied among the participants, the longest time course of placement spanning 11 years.

With the established clinical diagnosis (code*: clinical diagnosis*), the individuals receive the means for finding new remedies and ways of coping: *"The diagnosis presented an end to the process for me, a kind of relief. I was finally able to talk about it, what it actually was,* *and is there anything else I can do to help myself. They also taught me how to live with it and make it easier for me to function."* As observed in the example, the diagnosis represents a great relief for the patients, a sense of completion to the process of finding the answer to their health problems (code: *support*), with the pain finally given its true meaning (code: *making sense of pain*). The results are consistent with the findings of A. Gill Taylor et al. (2016), where they found, through qualitative research, that diagnosing represents alleviation to the patients. Most patients with chronic pain face symptoms with an avoidance of coping, which can be proven beneficial for a short period of time, but the long-term results reveal that avoiding leads to a greater degree of physical limitations. Meanwhile pain acceptance is associated with a lesser degree of perceived pain, distress, and physical limitations (Rodero et al., 2011). The findings of our research are therefore in concord with the findings of others. As long as limited physical capabilities allowed functioning without major changes, participants avoided facing problems.

When the symptoms exceeded the difficulty level within which they could no longer function, they sought medical attention. The continuum between the diagnosis and the coping included several steps, beginning with the general understanding of the disease, comprehending the new behaviour, and later, accepting the disease, thus enabling the formation of coping strategies. With psycho-education, which is a part of the process of diagnosing, comes the third period of confrontation with the syndrome. The knowledge about the nature of the disease has the effect of reducing the levels of fear, allowing the individuals to begin the process of acceptance: *"Then you try to come to terms [with the syndrome]. There is simply something wrong with you, the pain shall remain forever. This will not change. You need to make the most of it. But you do know that there is nothing physically wrong with you, that this is not something that will get worse and endanger you. (U4)"*

As cited by the findings of a study by W. R. Neilson and M. P. Jensen (2004), our data also confirmed that acceptance, self-initiated, and motivated behavior are critical to successfully coping with fibromyalgia symptoms. The treatment includes both the professional medical monitoring, and high levels of patient involvement in the whole process of the adapted way of functioning. L.R.-M. Hallberg and S. G. Carlsson, (2000) state that a number of lifestyle adjustments are required to successfully cope with symptoms, which is, again, consistent with our findings. Participants used various behaviours and coping strategies on their own initiative in an effort to reduce symptoms (category: *adjustments*). They introduced various changes into their daily lives, such as regular physical activity (walking, swimming, cycling), massages, changes in diet, and professional medical treatment (psychological, psychiatric, physiotherapeutic treatments). *"Formal treatment includes a treatment at the Soča Rehabilitation Institute, a psychological and psychiatric treatment, and* *physiotherapy. In addition, I exercise twice a week. I joined a society to have company on the trips we take, I go for a massage once a month.* (U2)*"*

The level of mood improves, there is less fear present, and the general behaviour is more motivated and goal-oriented (code: *motivation*). Individuals gradually begin to focus their attention on bodily perception, which helps them adjust their behaviour (code*: body awareness*). Dedicating time to oneself, caring for oneself, showing compassion for oneself, as discussed by J. Kabat-Zinn (1990), help individuals to become more aware of themselves and what is happening around them. The same is noted by M. R. Leary et al. (2006), namely that by increasing behavioural awareness, we create a break in the stimulus-response relationship that is characteristic of automatic responses, and thus the *response* (behavioural component) is separated from *stimuli* (causal component). Coping methods are based on individually designed strategies that are in line with the patient's capabilities and needs. L. R.-M. Hallberg and S. G. Carlsson (2000) also emphasized the importance of a patient-centred approach in their work. Changes in functioning on the social level are also visible, as the patients learn to set boundaries in relationships and set priorities more consciously: *"In relationships, I stand up for myself better, saying 'no' is no longer difficult for me. You try not to need any help. But sometimes I simply do need it. And I learned how to ask for it. If something doesn't work for me, I ask about it through a game or conversation. I use my chance.* (U2)*"* Despite learning new behavioural patterns, fibromyalgia patients remain a vulnerable group for experiencing stigmatization (code: *stigmatization*), which is consistent with the research literature describing the ignorance and insensitivity of health care professionals and the environment due to the invisibility of fibromyalgia symptoms. Patients are subject to doubts about them self and their health and accusations from others (Gill Taylor et al., 2016).

Despite the efforts that the patients input via the coping strategies (code: *physical limitations)*, fluctuations in experience and behaviour occur. Falling into previous behavioural and cognitive patterns of functioning, has the effect of worsening the mood and increasing the intensity of the symptoms (code: *disappointment*). With the aggravation of the symptomatology, the patients are further accompanied by disappointment, anger, anxiety, and general sadness. The unpleasant emotions are directed towards the person exhibiting them, which in turn affects one's self-image (Galvez-Sánchez et al., 2019). "*I used to and still have a guilty conscience about my tasks not being solved good enough. It affects my well-being immensely. It's hard to accept that you cannot do everything. Because I want to do more. Then, out of this yearning, we try to ignore the pain a little, but within a few seconds it reappears in an even more severe form.* (U4)*"*

Theoretically, we could allow for a possible existence of an additional stage where FM patients mostly function according to the acquired new (cognitive, behavioral and emotional) patterns, but it could not be sufficiently confirmed with the data gathered. The final step in dealing with the disease can be set as *achieving optimal functioning* within the grasp of the disease. When the newly learned behavioural and cognitive patterns stabilize, the rate of fluctuation in patients' behaviour, emotions, and physical limitations, from pain to fatigue, is consequently reduced. Given the course of the disease, we therefore assume that with stabilized behavioural patterns, such as the establishment of social boundaries, in the sense that individuals feel better understood by the environment in which they are situated and that their surroundings take them into account, the patient may indeed develop a finalised manner of coping with the process that is the fibromyalgia syndrome.

4.3 PHYSICAL AWARENESS IN THE CONTRIBUTION TO THE RECOVERY PROCESS

The concept of recovery may indicate the processes of transition from illness to absence of illness or the return to yet another physical and/or mental state. Recovery is connected to the concept of illness, health, and social roles (Mengshoel and Heggen, 2004). The results reveal that the recovery process begins with an established clinical diagnosis, patients gain insight into the nature of the disease, and can begin the process of accepting, and finding appropriate strategies to manage symptoms. The chronic nature of the syndrome may contribute to patients gradually incorporating the pain into their perception of identity (Compañ et al., 2011). Through appropriate medical treatments and the stabilization of newly learned behavioural, cognitive and emotional patterns, patients attempt to successfully regulate the symptoms of the disease, which is consistent with the findings of A. M. Mengshoel and K. Heggen (2004). The recovery process in fibromyalgia is slightly different, as there is no definitive cure for the eventual absence of symptoms (Gill Taylor et al., 2016). The key factor in the entire recovery process is physical awareness. Through the analysis of body map images, we gained additional insight into body perception, which is present more holistically in pleasant situations, where contact with one's own body is established, while in a state of severe pain the body is perceived as more differentiated or even 'dissociated' from perception. Dissociation tends to remove our awareness from our in-the-body, here and now physical experience. Patients with chronic pain often have difficulties and attending to physical experiences (Price and Mehling, 2016). We found that greater physical awareness contributes to a mitigated expression of symptoms, as patients can predict and influence them through a change in behaviour, which is consistent with literature findings, stating that with an increase in awareness, the ability to direct behaviour also improves (Leary et al., 2006). The findings of this paper can be further connected to the accepting way of coping with symptomatology, mentioned above (Rodero et al., 2011).

During the period of aggravating symptoms, participants perceive their body as conflicting with their intentions, expectations, and the social and physical world around them (Ashe et al., 2017). Chronic pain, as in fibromyalgia, alters experiences at the physical level of the body and body awareness (Calsius et al., 2015). In moments of noticeably worsened pain, the participant’s awareness of the body changes, as the pain takes over the experience. The functioning as a whole is arduous and tiring. As described in the study by C. Valenzuela-Moguillansky (2013), patients during such a period of severe pain, describe their bodies as persistently ‘heavy’ and ‘tired’, in the framework a *global felt sense*, namely, through a description of one’s internal space living with fibromyalgia. As a result, a barrier is created between the body, the environment, the relationships outside of them, and emotional mood. The findings of our study show that during periods of perceiving severe pain, patients ‘dissociate’ themselves from their bodies, which in turn affects the altered embodied experience. This significant phenomenological experience, describing a general feeling of dissociation from the body, a sort of an absence of a connection between the body and mind, could coincide with the paradoxical experience of pain present, yet not perceived, as studied in further detail by C. Valenzuela-Moguillansky (2013) in patients with fibromyalgia. An experiential distance is created between the person and the body. These changes can be considered as a disturbance patients "body shema".

Another form of body perception in the state of deeply expressed pain, has been associated with the concept of hyper-embodiment (Calsius et al., 2015). The experience of the participants is completely taken over by pain and other symptoms such as physical fatigue, and impaired cognitive functioning. Distress is present on a physical, mental, and emotional level. They experience the psychological conflict as ‘overly real’ and thus feel the psychological pain as a physical manifestation. Participants experience the body uncomfortably, as a burden or weight. However, the mentioned concept can also allow individuals in positive situations to feel the body as very pleasant (Calsius et al., 2015), which is also additionally confirmed by the findings of our study. Under favourable conditions, the body serves as a source of pleasure (Calsius et al., 2015).

Another form of body perception in a state of deeply expressed pain has been associated with the concept of hyper-embodiment (Calsius et al., 2015). The experience of the participants is completely taken over by pain and other symptoms such as physical fatigue and impaired cognitive functioning. Distress is present on a physical, mental and emotional level. They experience psychological struggle as “too real” and thus feel psychological pain as physical. Participants experience the body uncomfortably, as a burden or weight. However, the mentioned concept can allow individuals in favourable situations to feel the body as very pleasant (Calsius et al., 2015), which is also confirmed by the findings of our study. Under favourable conditions, the body serves as a source of pleasure (Calsius et al., 2015).

Participants described the feeling of lightness and softness of the whole body, accompanied by feelings of joy, gratitude and happiness. In some cases, in a state of absence of pain, they described the distinctly light areas of the body as not belonging to them (*“as if the legs were not mine, they did not belong to my body”*). We hypothesize that abnormal perceptions of bodily lightness and a state of absence of pain, significantly influenced the altered perception of the body, which is expressed in the altered experience of ownership. Fibromyalgia patients harbour an unstable body schema, a negative biased perception of their own body, and an increased alertness for internal bodily signs. These manifestations can be interpreted as possible reasons for the inadequate updating of body perception (Martinez et al., 2018).

4.4 LIMITATIONS OF THE RESEARCH

We encountered several obstacles in the process of the study, but these limitation may serve as a guide for further studies. One limitation is that the specificity of qualitative and phenomenological research is based on the importance of the meaning of language. This presents the advantages and limitations of the study. The later may be because it is sometimes difficult to find an appropriate term to describe an experience, and because a single term may represent different meanings to different individuals. Quite often also the right understanding of the phrasing depends on the comprehension of the whole context.

Another encountered difficulties were in selecting participants. The Covid-19 pandemic made it challenging to find participants. In addition to FMS being a specific disorder, there was a need to find participants willing to search and explore in-depth experiences that can be both, pleasant and unpleasant. Sometimes one may, at first, assume she is prepared for an in-depth introspection, but latter she realizes that this is not the case. This happened with one participant, with whom we consequently researched only her positive experiences related to FMS.

Third, during the data analysis we encountered some difficulties, as well. Usually our experiences are complex and intertwined, and can therefore be challenging to place them into particular categories. It may thus seem that some examples of experience, presented above, are more difficult to see only within one category. Certain reports could be included in several categories simultaneously, as they contained descriptions of more than one category. Despite that, we tried to proceed as much as possible from the report's content when analysing the data.

Specific complications of the research are due to the pandemic of the new Coronavirus. Periods of quarantine and restrictions that affected the course of life made it impossible to obtain data quickly and with as many participants as planned. As a result, the data acquisition period was extended. In addition, both researchers and participants wore protective masks during each session, observed hygiene regulations, and observed social distance. With the necessary mitigation measures, we wanted to prevent the spread of the new coronavirus.

5 CONCLUSIONS

The aim of the study was to contribute an in-depth understanding of the experience of pain and other symptoms of fibromyalgia as a chronic pain syndrome, and to understand the process of coping with its symptoms. Furthermore, the paper wants to provide a deeper understanding of the ways body-perception awareness and the overall experience of illness affect patients with fibromyalgia.

It is crucial for fibromyalgia, as a chronic pain syndrome, to also be explored from a psychological and experiential perspective. The data obtained in the research has highlighted the aspect of social relationships and self-perception as an interaction that significantly contributes to and co-shapes the perception and experience of pain. Pain is a complex experience based on the biological level. The quality of life, according to our research, is not only biologically conditioned, but is in complex interaction between psychological, biological, and social factors. Phenomenological research has enabled us to transcend the biomedically-oriented research models and understandings of fibromyalgia and gain a richer insight into the experience.

The key experiential components that are part of the positive process of experiencing are social components based on understanding, connection, and acceptance, from which a positive self-evaluation ("I am enough") emerges. On the emotional, physical, and cognitive experience, a person perceives changes. While feelings of pleasant emotions, they observe lightness and reduce pain and fatigue in the body and increased mental clarity. Quality of life is formed, which encompasses a broader spectrum of experiencing relief in the direction of freedom and the belief that everything is ok. Involvement in social interactions is easy and light. They feel connected to the environment that includes nature, people and animals. The process is reminiscent of a positive feedback loop.

The results show that incorrect relationships, inaudibility when being overworked, and loneliness affect the way people experience and value themselves. The perception of self-experience, the situation in which they are, and the overall functioning of the person change. The desire for structure, pleasing, and perfectionism influence people into wanting to perform tasks effectively despite their current limitations, such as low mood and poor physical well-being. The limited capacities of the body do not allow this type of operation. Concurrently, feelings of anger, disappointment and powerlessness appear, with the individuals having problems at the level of cognition, also being exposed to varying degrees of intense pain and fatigue. At the peak of the process, people are unable to function properly and are unable to cope with everyday tasks.

The specific nature of phenomenological research lies in the mode of application of language. Clarity and rich use of language contribute to more comprehensive and diverse gathering of data that offer deeper insights into scientific inquiries. Phenomenology was thus deemed an appropriate method of researching experience for fibromyalgia. In order to limit the possible obstacles in verbal communication, a non-verbal body mapping technique was included in the research as well. Body map images have proven to be a vital method that complements and improves the breadth of insight into the content of the interviews. It enables abstract and graphic representation of concrete elements in the experience. In the cases of perceiving severe pain, the results showed different aspects of body awareness compared to the situations where the symptoms were less pronounced or completely absent. Although no generalization to the total population of FM patients can be made given the small size of the sample, these results provide insights into how people with fibromyalgia experience their bodies.

In general, not many studies have been done on the topic of experience in FM patients. Despite all the limitations, the findings of the research have a significant scientific value. The study represents the first micro-phenomenological study of in-depth analysis on the experiences of patients with FMS in Slovenia. By conducting additional research on the in-depth experience of FM patients, we could compare the data and get a broader insight into the experience. More knowledge and understanding of the experience of symptomatology could open up new ideas on treatment and effective coping with FMS.

6 DALJŠI POVZETEK V SLOVENSKEM JEZIKU

Sindrom fibromialgije (FMS) je kronično stanje, za katero je značilna razširjena mišično-skeletna bolečina in številni simptomi, vključno z utrujenostjo, motnjami spanja, kognitivno disfunkcijo in psihološkimi stiskami (Araya- Quintanilla idr., 2020). Definicija, klasifikacija in diagnoza sindroma med različnimi zdravniškimi združenji, zdravniki, psihologi in pacienti, ni poenotena (Häuser idr., 2012). Simptomi vključujejo razpršeno skeletno mišično bolečino vratu, ramenskega in medeničnega obroča, zgornjega dela prsnega koša, komolcev in kolen, ki izvira v globje ležečih mehkih tkivih (mišice, tetive, vezi) (Logar, 2011). Bolečine vključujejo obe strani telesa (Jahan idr., 2012) in je marsikdaj ne moremo natančno lokalizirati (Logar, 2011). Pacienti pogosto navajajo prisotnost nemirnega spanca, utrujenost ob prebujanju, občutijo otekanje okončin, glavobole, motnje koncentracije, spominske motnje, motnje v delovanju črevesja, tesnobo in / ali depresijo, zmanjšano aerobno kapaciteto in funkcionalnost vsakodnevnih življenjskih aktivnosti (Jahan idr., 2012).

Etiologija fibromialgije ostaja nejasna (Jahan idr., 2012). Pogosto je nastop sindroma posledica sočasnih sprožilnih dejavnikov, kamor vključujemo okužbe, dolgotrajen psihičen stres in čezmeren telesni napor. Prevalenca sindroma po svetu je različna, med 0,2 in 6,6% v zahodni družbi (Verbunt idr., 2008). Diagnoza sindroma fibromialgije sledi merilom Ameriškega revmatološkega združenja (ACR), ki so bila sprejeta leta 1990. Kriteriji vključuje odkritih 11 ali več od 18 priporočenih točk bolečnosti na pritisk. Bolečina je prisotna v mišicah ter mišično-skeletnih narastiščih, ter traja več kot tri mesece (Logar, 2011). Leta 2020 je ACR oblikovalo novo različico diagnostičnih kriterijev (Galvez–Sanchez in Reyes Del Paso, 2020). Pomanjkanje objektivnih označevalcev ali zanesljivih in veljavnih kliničnih ukrepov za diagnozo fibromialgije predstavlja velik problem v klinični praksi. Dokler ne bo več specifičnega znanja o etiologiji in patofiziologiji bolezni, se diagnoze postavijo na podlagi kliničnega ocenjevanja ter bolnikovega poročanja. Običajno lahko diagnoza fibromialgije traja več let, pri čemer bolniki obiščejo več različnih specialistov. V mnogih primerih diagnoza temelji na izključitvi drugih sorodnih bolezni (Galvez- Sanchez in Reyes Del Paso, 2020). Trenutno še ni razvitega standardiziranega zdravljenja. Terapije so usmerjene v zmanjšanje simptomov in ohranjanje posameznikove sposobnosti za optimalno delovanje (Araya-Quintanilla idr., 2020).

Namen magistrskega dela je bilo doprinesti k poglobljenem razumevanju doživljanja bolečine in drugih simptomov fibromialgije, kot kroničnega bolečinskega sindroma ter razumevanje procesa soočanja s sindromom. Predvsem nas je zanimalo razumevanje učinka ozaveščenosti telesnega stanja, razvoja in sprejemanja bolezni. Preko zastavljenih raziskovalnih vprašanj smo želeli raziskati poglobljeno doživljanje.

Raziskovalna vprašanja so naslednja:

Kaj in kako doživljajo osebe s sindromom fibromialgije v povezavi z boleznijo, v procesu od nastopa simptomov do sedanjega trenutka?

Kako se osebe s sindromom fibromialgije soočajo s to boleznijo?

Kateri so ključni dejavniki, ki pri osebah s sindromov fibromialgije poslabšajo ali izboljšajo simptomatiko bolezni?

Kako pripomore pomen telesne ozaveščenosti k procesu okrevanja ter kaj za posameznika pomeni proces okrevanja?

Raziskava je bila izvedena na vzorcu šestih žensk, s postavljeno klinično diagnozo FMS. Osrednjo tehniko zbiranja podatkov je predstavljal mikrofenomenološki intervju v kombinaciji s tehniko preslikave telesa (ang. »body mapping«). Specifičnost fenomenološkega raziskovanja je v načinu aplikacije jezika. Jasnost in bogata raba jezika pripomore k bolj obsežnim in raznolikim podatkom, ki nudijo globlje vpoglede v znanstvena vprašanja. Da bi omejili morebitne prepreke v verbalni komunikaciji smo v raziskavo vključili neverbalno tehniko telesnega zavedanja (body mapping). Slike preslikave telesa so se izkazale za pomembno metodo, ki dopolnjuje in dodaja k širini vpogleda vsebine intervjujev. Podatke smo s pomočjo metode kodiranja analizirali ter razvili dve poskusni teoriji. Poskusna teorija 1 opisuje ključne dejavnike in potek doživljanja v pozitivnih in negativnih situacijah. Poskusna teorija 2 se osredotoča na doživljanje in soočanje s FM simptomi, od prvega nastopa, vse do sedanjega trenutka.

Poskusna teorija 1:

Zasnovana poskusna teorija navaja, da je socialna komponenta začetni dejavnik, ki pomembno vpliva na razplet doživljanja situacije ter posledično tudi simptomatike. Model sicer predpostavlja, da pozitiven potek lahko temelji na dveh različnih začetnih stanjih socialnega sprejemanja.

Prvi način pozitivnega poteka doživljanja:
Ključne doživljajske komponente, ki so del pozitivnega procesa doživljanja so socialna komponenta, ki temelji na razumevanju in povezanosti s strani okolice. Socialna sprejetost in vzpodbudne okoliščine, kot je razumevajoče in sprejemajoče okolje vplivajo na doživljanja sebe, kot »*dovolj sem*«. Bolj prijetno doživljanje sebe omogoča, da se tudi osebe same (bolj) sprejemajo in doživljajo razbremenjenost v sedanjem trenutku. Situacijo telesno

doživljajo kot bolj lahkotno, brez potrebe po hitenju ob tem pa jih spremljajo prijetna čustva. Spremembe se kažejo na telesnem, kognitivnem in čustvenem nivoju. Kvaliteta doživljanja, ki smo jo pridobili skozi analizo, je zelo abstraktna ter se jo verbalno težko zajame. Ne opisuje samo razbremenjenosti pričakovanj do sebe, temveč širšo življenjsko svobodo, ki lahko vključuje tudi povezanost z drugimi bitji (tako ljudmi kot živalmi) ter širšim svetom. Sprememba doživljanja temelji na osnovnem prepričanju o svetu, da je vse v redu. Zdi se, da osebe za pozitivno vrednotenje sebe potrebujejo zunanjo potrditev, v obliki občutka, da so sprejete, razumljene ter del skupnosti. V kolikor se udeleženke počutijo, da so sprejete, bo izkušnja povezana z bolj celostnim telesnim zavedanjem ter manj intenzivno izraženimi simptomi, kot so bolečine, utrujenost in oteženo kognitivno delovanje. Kar je razvidno tudi iz slik preslikave telesa, kjer so udeleženke svoje zaznavanje s telesom upodobile bolj celostno ter pokazale stik s svojim telesom. Telo je prikazano kot celota, ki se z krožnimi in mehkimi linijami povezuje z okoljem. Prisotna je mentalna jasnost, lahkotne in prijetne misli, katere so sposobne nadzorovati, kar je prikazano z simboliko oblačkov, uporabo svetlih barv ter krožnih linij.

Drugi način pozitivnega poteka doživljanja:
Potek doživljanja opisuje, kako udeleženke iz začetne faze, ki je temeljila na socialnem nerazumevanju in nesprejetosti, preko zavestne spremembe doživljanja lastne vrednosti dosežejo pozitiven potek doživljanja. Udeleženke so prvotno negativne situacije spreobrnile na doživljanje v smer pozitivnega občutenje**,** kjer so znale in si upale drugače odreagirati kot v predhodnih situacijah. S pomočjo asertivnega vedenja so bile osebe sposobne postaviti meje v odnosih. Zavedanje, da se okolje ne bo spremenilo, vendar da lahko vplivajo na spremembo vedenja in dojemanja sebe, jim omogoča preskok v načinu vrednotenja sebe. Osebe spremenijo doživljanje okolja, tako da spremenijo svoja pričakovanja do okolja, preko postavljanja meja, morebitnega boljšega izražanja v komunikaciji ali odmika od nelagodnega doživljanja. Posledično čutijo lastno svobodno, občutijo moč in kontrolo nad lastnim funkcioniranjem. Telesno doživljanje je manj obremenjeno z bolečino in drugimi simptomi.

Negativen potek doživljanja:
Naslednji potek v doživljanju simptomatike predstavlja prisotnost zaznavanja izrazitejše bolečine, celostne utrujenosti, oteženega kognitivnega funkcioniranja ter znižano čustveno razpoloženje. Zaznavanje situacije v začetni fazi temelji na socialni komponenti: socialnega nerazumevanja, nepovezanosti in nefunkcionalnih odnosov. V primeru nesprejemajočih okoliščin zaradi želje po razumevanju, spoštovanju in potrditvi so udeleženke v večjem psihičnem in posledično tudi fizičnem stresu. Zviša se občutek nemoči ter dvomi vase. Iz doživljanja sebe, da nisem dovolj, se poveča občutek osamljenosti, prepuščenosti samemu sebi ter občutek sprejemanja dodatnih bremen in odgovornosti. Ob tem prihaja do sprememb

na telesnem, kognitivnem in čustvenem področju. Področja so v interakciji in hkrati sovplivajo druga na drugo. Obremenjenost vpliva na miselno prenasičenost. Spremlja jih jeza, razočaranje, strah in žalost. Opisan proces deluje kot negativna povratna zanka, ki poglobi doživljanje simptomatike in stiske. Doživete bolečine, občutek teže in utrujenost so udeleženke prikazale grafično na slikah preslikave telesa. Izpostavljeni so različni predeli telesa, ki nakazujejo na različne oblike bolečin in ostala neprijetna telesna doživljanja, kot so mravljinci, pomanjkanje energije in telesne napetosti. Prevladujejo hladni odtenki barv ter ostre linije. Slike delujejo nekoliko bolj pusto in hladno, kot slike pozitivnih izkušenj.

Poskusna teorija 2:

Zasnovana poskusna teorija 2 pojasnjuje načine soočanja in doživljanja FM simptomov, od nastopa do sedanjega trenutka. Vključuje tri razvojna obdobja, in sicer obdobje *zgodnjega procesa razvoja simptomatike, poglobitev razvoja simptomatike* in *soočanje s simptomatiko*. FMS vključuje poleg doživljanja kronično razširjene bolečine, kot prevladujoči simptom, tudi splošno izčrpanost, težave s spanjem in koncentracijo, ki pomembno vplivajo na vse aspekte človeškega doživljanja. Predpostavljamo, da osebnostna struktura pomembno vpliva na odzive posameznikov v stresnih situacijah ter lahko predstavlja predispozicijo za možnost razvoja sindroma v povezavi z ne vzpodbudnimi okoliščinami, kot so pretirane obremenitve ali nekorektni odnosi. Značilne osebnostne poteze, ki se pogosto pojavijo pri FM bolnikih, kot je tendenca k perfekcionizmu, visoka storilna naravnanost, višje izražen nevroticizem, nižja samopodoba ter potreba po samovrednotenju preko kompetenc in odobravanja drugih.

V obdobju *zgodnjega procesa razvoja simptomatike* osebe delujejo pod visoko stopnjo obremenitev. Telesno zaznavanje je v omenjenem obdobju zelo omejeno. Pozornost ni usmerjena na lastno telo, vendar na okolico ter obremenitve, s katerimi se soočajo. S poglabljanjem in stopnjevanjem preobremenjenega načina življenja se zmanjšujejo kapacitete za nemoteno vsakodnevno funkcioniranje. V obdobju *poglobitve razvoja simptomatike* se pojavijo bolečine ter celostna utrujenost v intenzitetah, ki vplivajo na oteženo in omejeno funkcioniranje. Bolečina, utrujenost in oteženo kognitivno delovanje prevzamejo in vplivajo na samopodobo, medosebne odnose in bolnikovo okolje. Zaznavanje telesa se usmeri v poglobljene bolečine in izmučenost telesa. S stopnjevanjem simptomatike se tudi poglabljata doživljanje osamljenosti in stiska. Ko simptomi začnejo prevzemati način funkcioniranja, pacienti poiščejo zdravstveno pomoč. Sam proces diagnoze je običajno časovno dolgotrajen ter zahteva številne obiske pri različnih specialistih. Postavljena klinična diagnoza bolnikom predstavlja razbremenitev. Sledi obdobje, ki smo ga poimenovali *soočanje s simptomi*. Kontinuum med diagnozo in spopadanjem vključuje več korakov, ki se začnejo z razumevanjem bolezni, spreminjanjem vedenja, sprejemanje bolezni ter oblikovanja strategij spoprijemanja. Kljub trudu, pacienti poročajo o nihanju v počutju in zaznavanju simptomatike. Zapadanje v predhodne vedenjske, čustvene in kognitivne vzorce funkcioniranja, vpliva na znižanje razpoloženja ter zvišanje intenzitete simptomatike.

Dodatno nas je še zanimal pomen telesnega zavedanja in proces okrevanja v okviru FMS. Koncept okrevanja lahko kaže na procese prehoda iz bolezni v odsotnost bolezni ali vrnitve v drugo fizično in / ali duševno stanje. Okrevanje je povezano s konceptom bolezni, zdravja in socialnih vlog (Mengshoel in Heggen, 2004). Glede na potek bolezni predpostavljamo, da se ob stabilnih vedenjskih vzorcih, kot je vzpostavljanje socialnih meja, v smislu, da se osebe počutijo bolj razumljene s strani okolja v katerem so ter jih upošteva, lahko pacient razvije končen način soočanja v procesu sindroma ter se uspešno sooča v procesu okrevanja.

Preko analize body map slik smo dodatno dobili vpogled v telesno zaznavanje, ki je v prijetnih situacijah prisotno bolj celostno, vzpostavljen je stik z lastnim telesom, medtem ko je v stanju hude izraženosti bolečine telo zaznano bolj diferencirano ali celo »disociirano« od zaznavanja. Ugotovili smo, da večje telesno ozaveščanje doprinese k manjšem izražanju simptomatike, saj pacienti lahko napovejo in vplivajo na simptome, preko spremembe v vedenju, kar je skladno z ugotovitvami literature, da se s povečanjem zavedanja tudi poveča sposobnost usmerjanja vedenja (Leary idr., 2006).

V obdobju poglabljanja simptomov udeleženke dojemajo svoje telo kot konfliktno z njihovimi nameni, pričakovanji ter socialnim in fizičnim svetom okoli sebe (Ashe idr., 2017). Ugotovitve naše raziskave kažejo, da se pacienti v obdobjih zaznavanja hude bolečine t.i. "disociirajo" od telesa, kar vpliva na spremenjeno utelešeno izkušnjo. Ta posebna fenomenološka izkušnja, ki opisuje "disociiranje" od telesa, predstavlja odsotnost povezave med telesom in umom. Druga oblika zaznavanje telesa v stanju poglobljeno izraženih bolečin smo povezali s konceptom hiper-utelešenja (hyper-embodiment) (Calsius idr., 2015). Doživljanje udeleženk popolnoma prevzamejo bolečine in drugi simptomi, kot je telesna utrujenost in oteženo kognitivno funkcioniranje.

Fibromialgija, kot sindrom kronične bolečine, je ključno raziskovati tudi iz psihološkega in doživljajskega vidika. Fenomenološko raziskovanje nam je omogočilo, da presežemo biomedicinsko usmerjene modele raziskovanja in preko razumevanja FMS izkušnje pridobimo bogat vpogled v doživljanje. Tako lahko izpostavimo, da je fenomenologija ustrezna metoda raziskovanja doživljanja za FMS. Študija predstavlja prvo mikrofenomenološko študijo poglobljene analize izkušenj bolnikov s FMS v Sloveniji. Z dodatnimi raziskavami o poglobljenih izkušnjah bolnikov s FMS bi lahko pridobili širši vpogled v doživljanje. Več znanja in razumevanja izkušenj bi lahko doprineslo nove ideje za uspešno spoprijemanje in zdravljenje s FMS.

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IZJAVA O AVTORSTVU MAGISTRSKEGA DELA

Spodaj podpisana Laura Jereb, z vpisno številko 89192014, vpisana v študijski program Uporabna psihologija, 2. stopnja, sem avtorica magistrskega dela z naslovom:

Experiential components of fibromyalgia: Phenomenological understanding and awareness of the experience of symptoms

S svojim podpisom zagotavljam, da je predloženo magistrsko delo izključno rezultat mojega lastnega dela. Prav tako se zavedam, da je predstavljanje tujih del kot mojih lastnih kaznivo po zakonu.

Soglašam z objavo elektronske verzije magistrskega dela v zbirki »Dela FAMNIT« ter zagotavljam, da je elektronska oblika magistrskega dela identična tiskani.

Laura Jereb