DPsych thesis

The intersubjective experience of women with chronic primary pain

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Full bibliographic citation: Mena Garcés, C. 2022. The intersubjective experience of women with chronic primary pain. DPsych thesis Middlesex University / New School of Psychotherapy and Counselling (NSPC)

Year: 2022

Publisher: Middlesex University Research Repository

Available online: https://repository.mdx.ac.uk/item/10yzv3

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The intersubjective experience of women with chronic primary pain

Submitted to the New School of Psychotherapy and Counselling and Middlesex University Psychology Department in partial fulfilment of the requirements for the Degree of Doctor of Counselling Psychology

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September, 2022 London, United Kingdom

Statement of Authorship

This dissertation was written by Catalina Mena Garces and gained ethical approval from the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University.

It is submitted in partial fulfilment of the requirements of these institutions for the Degree of Doctor in Counselling Psychology. The author reports no conflicts of interest and is solely responsible for the content. This work has not previously been accepted in substance for any degree and has not concurrently been submitted in candidature for any degree.

Acknowledgements

First and foremost, I would like to thank and express my deepest appreciation to all the participants who had the courage and kindness to share their accounts.

This endeavour would not have been possible without the ongoing support of my supervisors, Neil Lamont, who offered invaluable advice and the encouragement and guidance to steer me towards the finishing line. Julie McCarthy, who first introduced me to hermeneutic phenomenology, thank you for your appreciated suggestions and motivating guidance. I would also like to acknowledge and express my gratitude to Pamela James and John Bennet who offered support during the first stages of this journey.

Special thanks to NSPC, the teaching and admin staff for their ongoing support and patience. I am also grateful to my classmates with whom I shared many thoughts, and feelings throughout this process.

I would also like to thank Amanda George for her editing help and helpful feedback.

I could not have undertaken this journey without the amazing support from my loved ones. My family, in-laws, my friends and Mélida. Thanks so much for being there, for your help and your ongoing encouragement.

To my husband, Laurent, words cannot express my gratitude for your patience and loving encouragement, I wouldn’t be where I am today without all of your constant love and support. Amélie and Tristan, you have grown up alongside this journey, from young children to amazing cheerleaders. I hope I will make you proud.

"Pain and suffering are a kind of currency passed from hand to hand until they reach someone who receives them but does not pass them on."

Simone Weil

CONTENTS

Abstract

Although a universal experience, the sensorial and emotional aspects of pain have led to an emphasis on the inner and private aspects of the phenomenon, overlooking the essential aspects of the shared reality of pain. To date, there has been little research emphasising the intersubjective experience of chronic pain.

This hermeneutic-phenomenological study has been designed to provide an insight into the intersubjective experience of women with chronic primary pain.

Eight women who fit the diagnosis criteria of chronic primary pain were interviewed for this study and their transcriptions were analysed using van Manen’s (1997) hermeneutic-phenomenological approach. Three interrelated overarching themes were identified. The first theme, **“I cannot”: pain and the arrested self,** describes the experience of pain as an omnipotent and omnipresent force that imposes limitations that confine the pain sufferer to a place of powerlessness and separation from the world. The second theme, “**I am not"; the lost self and meaning-making,** describes the process of navigating through the grief for the lost self and identity, as well as the process of acceptance and resignifying one’s experience. Lastly, the third theme, “**This is real”: the need to be legitimised**, describes the lack of opportunities and obstacles preventing the experience of chronic pain from being validated and ultimately legitimised as real and debilitating.

The findings were integrated and discussed from a phenomenological tradition that permitted analysis of the experiences of chronic pain in women as they were lived phenomenologically – embodied and situated in the intersubjective lifeworld. Ultimately, the findings expose a general experience of not belonging and separation from the same world that the women paradoxically inhabit.

The assumption that pain is a private and subjective experience, and therefore inaccessible and ineffable, will continue to present as a barrier to the understanding of pain, as well as its approaches to treatment and care. Reconsidering pain as the product of a negotiated interrelatedness that takes place in a situated world offers a new and necessary avenue for understanding and pain care.

Keywords: pain, women, intersubjectivity, phenomenology, lived experience, hermeneutic-phenomenology

CHAPTER 1: INTRODUCTION AND BACKGROUND

Pain changes

Since the onset of this research, two important events have taken place in the field of pain. The first one was the approval of the revised International Association for the Study of Pain's (IASP) definition of pain, which was the result two years of deliberation and effort. In July 2020 the IASP published the revised definition of pain, as well as the keynotes, which aim to provide further context (Raja et al., 2020).

This revision aligns with the new classification of chronic pain by the eleventh revision of the International Classification of Diseases (ICD-11), the second big event that I witnessed as a researcher. Based on extensive research and data collected over six years by the International Association for the Study of Pain (IASP) Task Force, a new classification system for chronic pain was created. During the 72nd World Health Assembly on 25 May 2019, the World Health Organization (WHO) officially endorsed the ICD-11, which includes a new classification system for chronic pain. Included in this category is the new diagnosis of *chronic primary pain*. This new classification is the result of a bio-psycho-social approach, whereby chronic pain is treated as a disease in itself or a long-term condition rather than a symptom. This new understanding of chronic pain therefore has considerable treatment implications (Nicholas et al., 2019).

As a researcher, I found myself witnessing an important landmark in the history of pain research, which denotes the early attempts to challenge the existing dominant Cartesian dualism that has pervaded our understanding of human experience, especially when it comes to phenomena of health and illness.

It is for the same reason that this research is a timely and relevant effort to contribute to the understanding of chronic pain and its implications for treatment and care plans.

At the same time, it is important to recognise and remain cognisant of the fact that pain is a complicated topic. As Jackson (2005) states, pain is a liminal experience and, as such, its definition will inevitably fall into the trap of dualism. The author argues that when a phenomenon such as pain fails to fit into specific categorisations (in this case, mind versus body), then it inhabits the "between", which alters a sense of order and purpose. With the aim of alleviating the anxiety of the in-between, liminal phenomena are forced into categories to regain a sense of control and order. The mind–body dualism is a pervasive paradigm in Western culture, whereby, according to Kirmayer (1988), psychosomatic approaches only manage to assimilate their narratives to this dualism, as opposed to reforming its practice, and they continue to use categorical language such as physical and mental or real and imaginary.

In the same manner, Leach (1989) would argue that the world is a representation of our language categories, and not the other way around, and this stands true when finding oneself in a position of wanting to escape dichotomies but ultimately being limited by them. Language is a tool but at the same time a limitation when wanting to convey what pain is and how pain is experienced. However, as this research intends to demonstrate, the possibility to overcome these limitations imposed by dualism is possible when we learn and make a conscious effort to view through the lens of a different paradigm, less limited by the need for categorisation.

Although there is not sufficient time and space to explore and discuss the problems and challenges presented by Cartesian dualism, it is important to clarify that my position as a researcher is in agreement with Geniusas (2020), who understands pain as neither purely physiological nor purely psychological but as a "mosaic of physiological, psychic, cultural, historical, and social factors, unified in the framework of the personal meaning" (p. 170). More importantly, it is relevant to recognise that the subject in pain is, as with all its human experiences, a person in the lifeworld, which from a phenomenological standpoint is fundamentally intersubjective.

Pain is a word that contains myriad phenomena; hence, it has been the subject of many disciplines and, as an experience, it has been constructed by different historical discourses such as theological, medical and psychological. Bourke (2014) would argue that not only medical discourses but also philosophical ones have, through different analyses, assigned to pain the quality of an independent entity, an "it", which creates an ontological fallacy. From a historical standpoint, Bourke understands pain as a "type of event" and, as such, an occurrence in the subject's life that constitutes the self and the other. Pain is the way we perceive an experience; it is not the injury but how we evaluate the injury. As Bourke (2014) points out, pain is an activity, something that we all do in different ways, since "pain is practised within relational, environmental contexts. There is no decontextual pain-event" (p. 8). However, from the nineteenth century onwards, medical discourses began to reduce pain to a sign or symptom, which, aided by modern technologies, eradicated the person-in-pain and the meanings assigned to the experience.

Understanding pain as a contextualised, relational and intersubjective event, which is also historical, cultural and social, is necessary to understand the experience of pain in women since gender differences can moderate the pain experience. These differences used to be mostly assigned to biological mechanisms; however, nowadays, psychological and social mechanisms have also been considered important factors (Keogh & Herdenfeldt, 2002). According to Stanier and Miglio (2021), stereotypes about gender influence the way that people estimate the experience of pain in others, which can lead to inaccurate assessments and treatment recommendations. Despite these contextual considerations, psychological variables that could account for the experience of pain are still reduced to cognitive processes or intra-psychic mechanisms.

Similarly, social aspects of pain include elements of culture and religion but have not been fully developed in pain research, overlooking its intersubjective and political elements. In recent decades, more interest in pain as a social phenomenon has been evidenced but this has been addressed from a psychological and neuroscientific standpoint (Sturgeon & Zautra, 2016). One could argue that, as well as pain, intersubjectivity and what we understand as "the relational" also fall into the liminality of the in-between. The attempts to understand pain from a bio-psycho-social model inevitably fall into the separation of these realms, as opposed to an approach that considers integration and seeing more than the sum of the parts.

By understanding pain as an experience of the lived-body, the separation between the realms of the physical, the mental and the social disappears. Pain is therefore an experience that is engaged and situated, no longer a phenomenon that is merely private and inaccessible, whereby the subjective experience is constructed in the intersubjective space.

The current understanding of pain

To date, the efforts to define and classify pain should not be underestimated and, despite these ongoing efforts, several pain researchers have criticised this Sisyphean task. Sir Gordon Holmes (1950), one of the great figures in the history of 20th-century neurology, agreed that a definition of pain "that would at the same time be adequately inclusive and sufficiently restricted is scarcely possible" (p. 18).

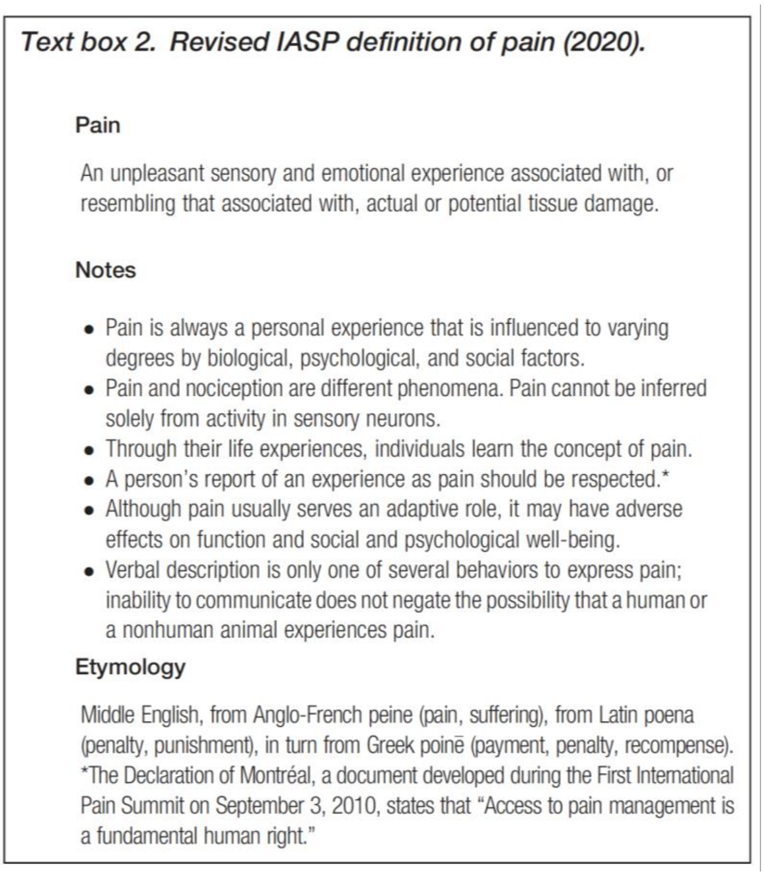
From this perspective, achieving a definition of pain means having to overcome the challenges of its mysterious nature and the linguistic barrier when it comes to expressing the experience (Cohen et al., 2018). Despite these obstacles, in 1979 the International Association for the Study of Pain (IASP, 2012) attempted to provide a universal definition of pain, approving the following definition: "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (Raja et al., 2020, p. 1).

This definition has been widely accepted and used not only by healthcare professionals and researchers in the pain field but also by other governmental and non-governmental organisations such as the World Health Organization. During recent decades many advances in the understanding of pain have taken place, leading to a revision of the current definition. In 2018 a Task Force was created by the IASP to evaluate the current definition of pain and to decide whether this should be kept or modified. This process took two years of analysis, revision and recommendations. Several definitions were proposed to fill the current gaps or address the main criticisms. For Cohen et al. (2018), to cite an example, the old definition continued to reinforce the Cartesian paradigm of body–mind dualism, making an explicit association between pain and tissue damage and evidencing a tension between self-report and the observer's perspective. With this in mind, the authors proposed an alternative definition that conceives pain as "a mutually recognisable somatic experience that reflects a person's apprehension of threat to their bodily or existential integrity" (p. 6). As opposed to the IASP definitions, the authors steered towards a phenomenological understanding of the experience of pain, understanding the phenomena as a shared experience where beliefs, expectations and perceived meanings attached to the experience of pain can be mutually explored, evidencing the inherent intersubjectivity of the pain experience.

Regarding the previous criticisms, other authors observed that the old definition did not account for the ethical dimension of pain and did not properly address the experience of pain in neglected or disempowered populations (Raja et al., 2020).

Ultimately, this long process culminated in a new recommended definition of pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage"(Raja et al., 2020, p. 4). The definition was expanded by six keynotes and the etymology of the word "pain" (see Figure 1). The revised definition was unanimously accepted by the IASP Council in early 2020.

Figure 1. Revised IASP definition of pain (2020)



Text box 2. Revised IASP definition of pain (2020).

Pain

An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.

Notes

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person's report of an experience as pain should be respected.*
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain.

Etymology

Middle English, from Anglo-French peine (pain, suffering), from Latin poena (penalty, punishment), in turn from Greek poinē (payment, penalty, recompense).
*The Declaration of Montréal, a document developed during the First International Pain Summit on September 3, 2010, states that "Access to pain management is a fundamental human right."

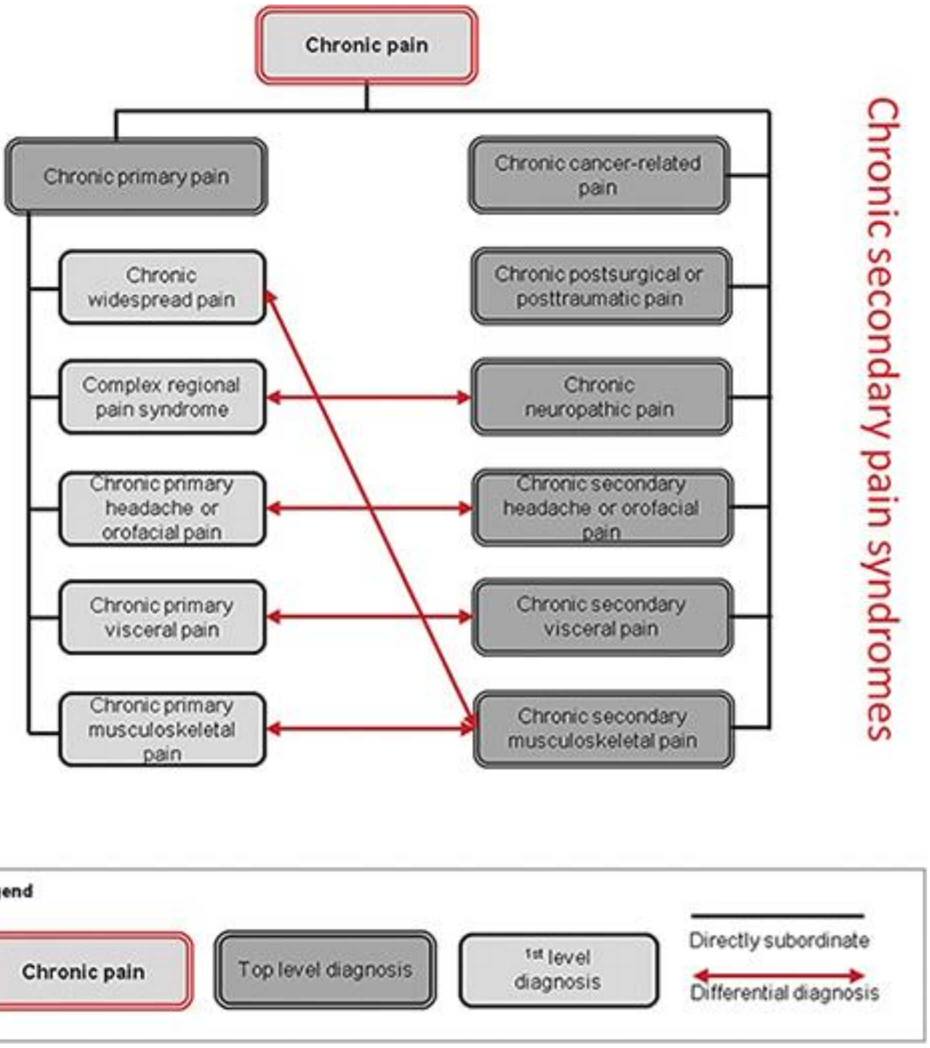
Note: Revised IASP definition of pain (2020). Reprinted from "The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises" by S. Raja et al., 2020, *PAIN (161)*9, p. 2. Copyright © 2020, © 2020 International Association for the Study of Pain. Reprinted with permission.

Chronic pain: a new classification

Chronic pain refers to the type of pain that persists past its normal healing time; therefore, it does not have the acute warning function of physiological nociception (Treede et al., 2015). In this sense, chronic pain has no biological utility, is seldom diagnosed and is very resistant to medical treatment. This means that the experience of chronic pain usually involves a long, tedious and painful journey of diagnosis that works mostly through exclusion criteria and results in futile attempts at treatment (Smith & Osborn, 2007).

The previous version of the International Classification of Diseases (ICD-10) of the World Health Organization (WHO) included some diagnostic codes for chronic pain conditions that did not reflect the actual epidemiology of chronic pain, and the categories established by the ICD-10 lacked a rational principle that suits the different types of chronic pain. Chronic pain was categorised by location, aetiology or the primary affected anatomical system, but even with these criteria some conditions such as fibromyalgia have challenged this systematisation (Treede et al., 2015). The IASP Task Force contacted the WHO in 2012 with the idea of creating a new classification for chronic pain that was more useful in a clinical setting in the areas of pain management and primary care. The efforts of pain experts recruited around the world resulted in a new chronic pain classification that has now been included in the latest ICD-11 category for chronic pain. This new classification conceives chronic pain, which is the sole or leading complaint, as a disease in its own right, and this is what is understood as the subgroup of **chronic primary pain.** For the other six subgroups, pain is initially conceived as a symptom of an underlying disease, therefore forming **chronic secondary pain** (see Figure 2). This distinction is relevant in the sense that it has important implications for the treatment and management of chronic pain conditions (Treede et al., 2019).

Figure 2. Structure of the IASP classification of chronic pain (ICD-11)



Note: Structure of the IASP classification of chronic pain. Reprinted from "Chronic pain as a symptom or a disease: the IASP Classification of Chronic Pain for the International Classification of Diseases (ICD-11)" by R. D. Treede et al., 2019, *PAIN, 160*(1), p. 21. Copyright © 2019, © 2018 International Association for the Study of Pain. Reprinted with permission.

According to Nicholas et al. (2019), this new definition of primary chronic pain, which will be discussed in detail in the next section, aims to avoid the dichotomy of physical versus psychological by accepting that many chronic pain conditions, which aetiology and pathophysiology can be difficult to decipher, are the result of a complex relationship between biological, psychological and social factors. This new definition aims to replace current medical terminology such as “somatoform”, “functional” and “nonspecific”, which can be vague and ambiguous, and conceive long-term pain as a condition in its own right.

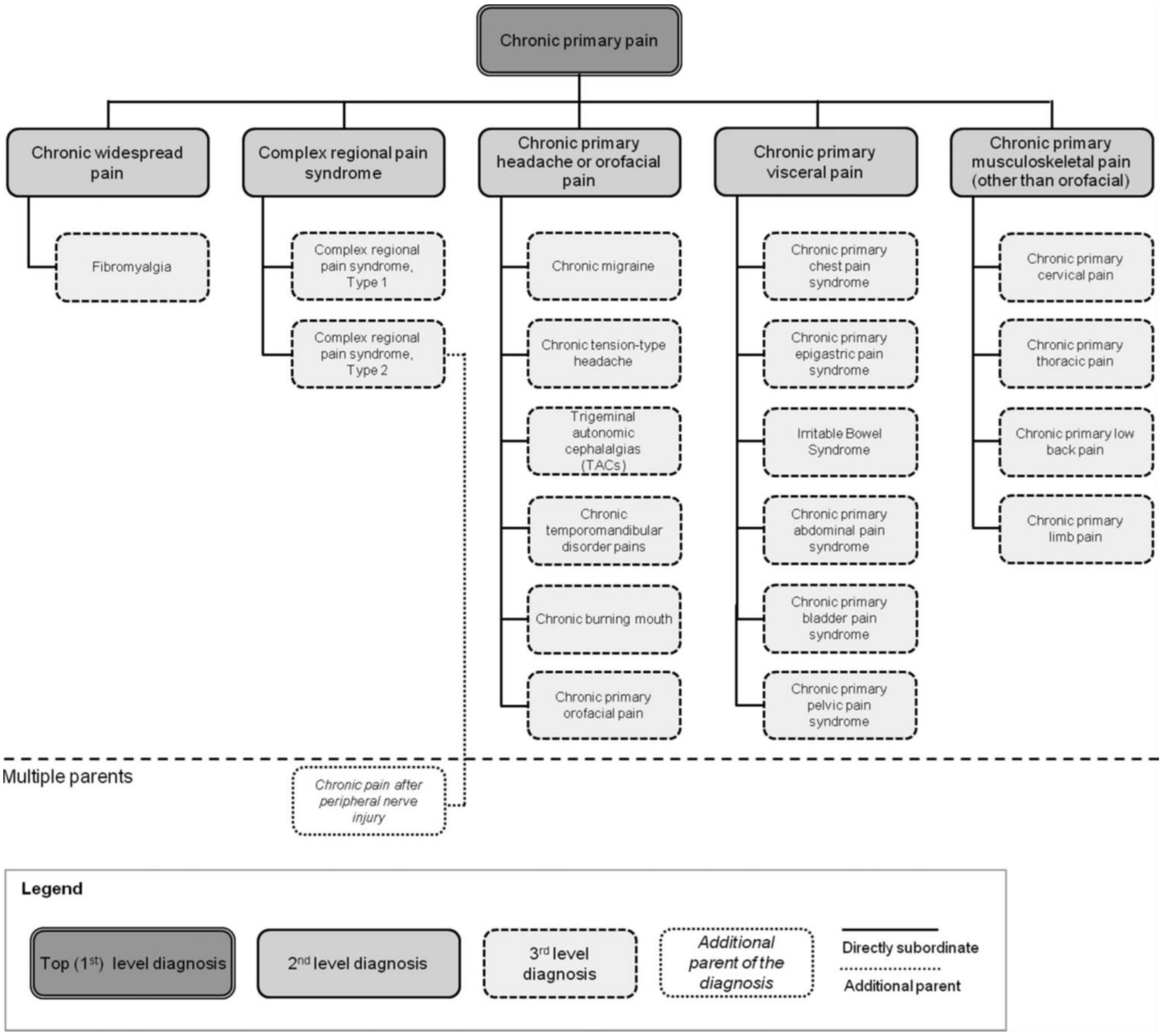
Chronic primary pain

Chronic primary pain (CPP) refers to pain in one or more anatomical regions that persists or recurs for longer than three months and which is usually associated with significant functional disability, interfering with daily life and social roles. In addition, this type of pain is associated with great emotional distress such as depressed mood, anxiety, anger and/or frustration. The diagnosis of CPP can be made independently of identified biological or psychological contributors unless another diagnosis would better account for the presenting symptoms.

Chronic primary pain can affect any body system (e.g. nervous, musculoskeletal and gastrointestinal), any body site (e.g. neck, abdomen, back, pelvis, thorax, urogenital region) or a combination of body sites, such as widespread pain.

In order to facilitate diagnosis, the ICD-11 describes the following five subgroups of chronic primary pain, as illustrated in Figure 3.

Figure 3. The general structure of the classification of chronic primary pain



Note: The general structure of the classification of chronic primary pain. Reprinted from "The IASP classification of chronic pain for ICD-11: chronic primary pain" by M. K. Nicholas et al., 2019, *PAIN, 160*(1), p. 30. Copyright © 2019, © 2018 International Association for the Study of Pain. Reprinted with permission.

I. <u>Chronic widespread pain</u>

This refers to a diffuse musculoskeletal pain in at least four of five body regions and at least three or more body quadrants (upper–lower/left–right side of the body) and axial skeleton (neck, chest, back and abdomen). It is usually associated with other medical conditions such as obesity, diabetes, sleep disturbances and hypertension. Fibromyalgia is one of the most commonly encountered forms of chronic widespread pain (Cohen, 2017) and is often associated with cognitive dysfunction, sleep disorders and somatic symptoms.

II. Complex regional pain syndrome (CRPS)

This is characterised by pain in regional distribution and is generally associated with previous tissue trauma, albeit disproportionate to the trauma itself. CRPS may present with sensory changes such as hyperalgesia,[1] hypoalgesia,[2] oedema,[3] changes in the temperature and colour of the skin, and sweating, among others. There are two subtypes of CRPS: type 1, where there is no peripheral nerve injury; and type 2, where there is evidence of peripheral nerve damage. Generally, a history of trauma or injury can precede both types.

III. Chronic primary headache or orofacial pain

This is characterised by headache or orofacial pain that occurs at least 15 days per month for longer than 3 months. Different subcategories have been described under this group, including chronic migraine, chronic tension-type headache, trigeminal autonomic cephalalgias (unilateral head or face pain), chronic temporomandibular disorder, chronic burning mouth pain and chronic primary orofacial pain.

IV. Chronic primary visceral pain

This type of pain includes pain in the head/neck viscera of the digestive tract, in the thoracic area, in the abdominal region, from the viscera of the digestive system, and the pelvic region, involving the viscera of the digestive, genital and urinary systems. Examples of chronic primary visceral pain are non-cardiac chest pain, irritable bowel syndrome, bladder pain syndrome, chronic pelvic pain and chronic testicular pain.

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[1] Increased pain from a stimulus that normally provokes pain.

[2] Diminished pain in response to a normally painful stimulus.

[3] The build-up of fluid in the body's tissues.

V. Chronic primary musculoskeletal pain

This pain can be located in the bones, joints, muscles or tendons and is not better accounted for by a specific classified disease. One of the most common examples of this pain is chronic primary low-back pain.

The inclusion of this new CPP category in the eleventh version of the ICD represents a new development from the pre-existing ICD-10 category of "somatoform pain disorder", previously used to diagnose pain with unclear pathophysiological aetiology. The new category of chronic primary pain aims to avoid the dichotomy of physical versus psychological, intending to be more agnostic with regards to the aetiology, having a more bio-psycho-social approach (Nicholas et al., 2019). It is expected that this new approach to chronic pain will inform treatment interventions and outcomes and will encourage new ways of approaching health that are not limited to the treatment of chronic primary pain.

The rationale for the chosen topic

Nowadays, chronic pain is considered to be a chronic disease like asthma or diabetes. What differentiates chronic pain from other types of pain is that it persists over a long period and is resistant to medical treatments. In addition, it has been widely recognised that chronic pain can be greatly affected by environmental and psychological factors (National Institutes of Health, 2020).

The impact on the patient's quality of life of chronic pain conditions such as lower-back pain and osteoarthritis should not be overlooked; they represent one of the most important causes of disability worldwide, and it has been recognised by many governments that chronic pain is both a challenge and a major priority for healthcare systems (Fayaz et al., 2016).

From a societal point of view, it is paramount to understand pain not only as a sensory and emotional experience but also as a social and communicative event, where the individual and private pain experience is described, expressed and decoded in different forms, depending on the audience and context of that specific expression (Craig, 2015). Long-term physical pain can have a great impact on sufferers, not only because of the experience but also as a result of its invisible nature. This makes it difficult for the chronic pain patient to make others understand their suffering or consider their pain to be a legitimate condition, which results in further psychological distress (Edmond & Keefe, 2015).

The effects that chronic pain can have on the subject's relationship with others – including social withdrawal, the loss of specific family roles, the frustration of communication and not being believed – are not new (Hadjistavropoulos et al., 2011). These have been studied from different angles that consider the cognitive, emotional and social factors and their role in the experience of pain when relating to others.

Chronic pain patients are prone to suffer from stigmatisation which is usually experienced as discrediting responses from others. There is plenty of research that evidences the pervasiveness of stigma among the chronic pain group. Pain sufferers not only feel dismissed by healthcare providers but they also report feeling not believed by their partners, relatives and friends; they perceive hostility from their colleagues in their work environment and they usually feel blamed and misled by others (De Ruddere & Craig, 2016).

According to Fayaz et al. (2016), an estimated 43% of the population in the UK is affected by some form of chronic pain. This figure is likely to increase as the population continues to age. Among those affected, a good portion manage to remain highly functional without seeing their lives greatly affected or having to rely on the healthcare system. However, the same study reports that there are between 10.4% and 14.3%, which translates to 7 to 9 million people, whose reported chronic pain is either moderately or severely debilitating.

Furthermore, a study conducted in 2017 by Public Health England and Versus Arthritis (Versus Arthritis, 2021) found that people were more likely to suffer from chronic pain if they were living “in deprived communities, were from minority ethnic backgrounds, were women, lived with more than two long-term conditions or were older” (p.11). As well as social disadvantage, the study concluded that other life stressors such as adverse childhood experiences can be linked to chronic pain later in life.

Many chronic pain conditions such as fibromyalgia, osteoarthritis, chronic low-back pain and irritable bowel syndrome are more common among women. In the same manner, women are twice as likely to have autoimmune diseases (Angum et al., 2020), which can cause persistent pain, and are four times more likely to experience bladder pain due to cystitis and fibromyalgia. In addition, some chronic pain conditions only affect women, including vulvodynia and endometriosis (Dusenbery, 2018).

Women’s social roles can be important determinants of the incidence, severity and impact of chronic pain in their lives. Women tend to be more exposed to different and greater life stressors (physical and sexual violence, financial discrimination) than men in our society. Expectations, family and social roles associated with the female gender can put women at higher risk of developing chronic pain conditions (Versus Arthritis, 2021).

Despite the high number of people affected by chronic pain, a large part of them women, service provision for the management of chronic pain in the UK is considered inadequate, showing important shortfalls in the structure of pain specialist staff and services across the UK (McGhie & Grady, 2016). Moreover, studies have found that women often report having negative experiences with health professionals, reporting feelings of rejection, a lack of comprehension, disbelief or being given psychological explanations for their experiences of pain (Werner & Malterud, 2003).

McGhie and Grady (2016) also state that, like other services, the resources for pain-management services within the NHS are scarce and overstretched as a result of fiscal constraints and reduced local community resources. Furthermore, the authors propose that artificial boundaries between secondary and community services and ring-fencing funding need to be addressed by commissioning groups in order to avoid hindering the efficient use of funding.

Chronic primary pain conditions are characterised by significant emotional distress and suffering. In addition to the physical pain, isolation and guilt can have a very detrimental impact on sufferers' mental health. According to Tang and Crane (2006), there is an elevated level of suicidal ideation in people who suffer from chronic pain. Furthermore, the authors also found that females who suffer from pain were more susceptible to suicidal ideation and death by suicide, a thought-provoking finding considering that, in the Western world, deaths by suicide are more common among men.

In recent years there have been significant developments in the understanding of pain through clinical scientific research. Progress in pain neurobiology is necessary to understand the pain experience; however, it is not sufficient. It is for this reason that dedicated research on the psychosocial factors associated with the pain experience is needed to obtain a more complete understanding of chronic pain (van Rysewyk, 2017). The latter was initially suggested by Osborn and Smith (1998) when they stated that further research on the experience of pain was needed in order to obtain greater awareness of the personal meaning that the sufferers assign to their pain. It is this particular and individual meaning that plays a crucial role in what was defined by the authors as a subjective experience; and it was this approach to research that led to a large number of studies applying phenomenology, specifically IPA (interpretative phenomenological analysis) to the field of health and illness (Smith & Osborn, 2015).

Lima et al. (2014) and Traverso-Yepez (2001) state that, although the biopsychosocial model has helped to improve the conception of pain by understanding it as an individual experience, this model still relies on the mind–body split. By maintaining a fragmented conception of health and illness, the biopsychosocial model continues to explain pain from the methods of natural science, reinforcing and normalising aspects from the positive sciences. By doing this, pain becomes objectified and fragmented, which is evidenced in the type of care that the patient receives; it is for this reason that a phenomenological gaze on the phenomenon of pain needs to be incorporated.

Moreover, Lima et al. suggest that a phenomenological–existential approach is also needed to understand the subject as a unity, where body and mind are intertwined and co-constitute each other. The authors also propose that, although phenomenology is commonly used as a research method in the field of health, it is seldom used as a theoretical paradigm to understand the human experience aspect of it.

Similar to Lima et al., Stanier and Miglio (2021) echo this idea that most phenomenological attempts to describe pain experiences are "generally motivated to explicate general structures of pain, rather than seeking to integrate their account into a wider phenomenological tradition" (p. 103). The authors state that, in order to be good, a phenomenological enquiry needs to account for the intersubjective dimension of the experience of pain, acknowledging its social, cultural, political and intercorporeal elements.

The gap identified in phenomenological studies of pain calls for action to explore the experience of pain as an event that unfolds in the fundamentally intersubjective lifeworld. Pain is articulated in a shared-meaning reality, where others can respond (or not) to what is happening to the subject in pain (Cohen et al., 2018).

Broadening the conceptualisation of pain from an experience defined as quintessentially subjective, to one that can expand to its intersubjective dimension, will help with further understanding what it means, as a woman, to live with chronic primary pain. From this particular standpoint, this project aims to recognise the suffering of women by giving them a voice to express relationally what their experience of pain is. The aim is to contribute to empowering practices that challenge the current, predominantly medical, gaze of chronic pain, thus allowing the experience to speak for itself to create a coherent and meaningful narrative (Werner, Isaksen & Malterud, 2004).

This study aims to explore the lived experience of chronic primary pain in women, but, as previously mentioned, my commitment to make this a phenomenological articulation has led me to emphasise the inescapability of intersubjectivity.

Instead of taking intersubjectivity for granted as a quality of the lived experience, I want to put this at the fore, the lived experience as an experience of the world, understanding pain as a situated phenomenon that takes place in the intersubjective shared world.

Following this, this study aims to address the following question:

What is the intersubjective experience of women with chronic primary pain?

This study aims to offer some important insights into the experience of pain in women from a place of being-in-the-world. Understanding pain as an event that is contextual and relational will hopefully challenge the conception of pain as something that is both inaccessible and non-shareable. This phenomenological articulation attempt is expected to contribute to the growing area of research on chronic pain beyond the Cartesian division of mind and body, also addressing the division between what is considered subjective and objective. Consequently, it is expected that the findings of this research will be of interest to different disciplines associated with the study of pain, including health psychology, physiotherapy, counselling psychology and psychotherapy, among others.

Engaging with reflexivity

I knew from the very beginning of my doctoral studies that the topic of my dissertation was going to be something related to the body and the concepts of health and illness. I was – and still am – fascinated by the way that we exist in the world in an embodied and connected way with the world and others.

My early studies in psychology were deeply influenced by psychodynamic theories, and the concept of psychosomatics always captured my attention. This led me to write my undergraduate dissertation on the experience of cancer from a psychosomatic perspective, understanding illness as the result of bio-psycho-social processes, whereby the psychological spoke of the intra-psychic elements that accounted for the experience of illness.

When engaging with existential theories during my doctoral studies, I realised that the psychoanalytic understanding of psychosomatics was relying on the Cartesian division: the split between the *psyche* and the *soma*. According to Cohn (1997), the separation between body and mind comes from an intellectual exercise rather than the lived experience. From an existential standpoint, human existence is embodied; therefore, we are corporality.

Although my views are completely in alignment with those of Cohn, I feel that the world and language that we inhabit continue to reinforce the split between body and mind.

It took me some time to properly assimilate the idea of simultaneity as opposed to causality. The theory of the unconscious continues to offer good, enticing and popular narratives about the aetiology of mysterious illnesses, such as the one offered by Suzanne O'Sullivan's *It's All in Your Head. True Stories of Imaginary Illness,* where, through her illustrations of psychosomatic disorders, she explains how the mind can cause severe neurological symptoms. However we decide to signify illness, what is clear is that, as human beings, we strive for coherence, and we need categories and logic and linear thinking that can provide us with some kind of order. But, as Cohn states, we need to approach health and illness from the lived experience. The concept of embodiment cannot only be understood from theory; it also needs to be experienced from felt and relational sense.

I am particularly interested in women’s health, perhaps because, in my personal life, I have inhabited a world that has been mostly populated by women, and professionally I have always been drawn to working with women's services and groups. My first job in the UK, was within a counselling service for Latin American women affected by domestic violence. This experience was not only enriching but also an opportunity to witness the depth of gender inequality and its impact on women’s physical and mental health. During the years I worked for the NHS I had the opportunity one more time, to work with women’s groups, where I provided support for patients affected by gynaecological and breast cancer.

I have developed a special interest and sensitivity to the different injustices that women face on an everyday basis, particularly with respect to health. This meant that during my doctorate studies, my essays were usually focused around women’s issues.

Our differences have been overlooked and neglected for too long, our bodies misunderstood and our experiences psychologised. This made me realise that we need more knowledge and more understanding of what it means to be an embodied woman in the world.

I was initially interested in fibromyalgia because it was one of those diagnoses that, since medically unexplained, felt controversial and closely related to the psychosomatic phenomena. The more I read about the condition, the more I began to understand that this was not only about pain, but also about being believed, being validated. This was a second layer of suffering that felt necessary to address. I began to pay attention to psychotherapy clients who presented with undiagnosed conditions, and also other women's stories who suffered from different pain conditions such as menstrual pain, stomach pain, joint pain, and so on. As well as being interested in the “mysteriousness” of their conditions, there was something about normalising women’s pain that elicited a feeling of frustration and discomfort: something did not feel right and definitely not normal.

The way I conceived illness, and pain, in this case, shifted from the more intra-psychic or psychosomatic understanding to the contextual and intersubjective experience of chronic pain, how women's pain unfolds in the relationship with others and the world. Changing the lens of perception allowed me to become more aware of the reality of inequality, the lack of knowledge and the urgent need to do more, to know more about women's pain.

The idea of standing from a purely feminist epistemology seemed alluring; after all, I was perfectly aware of my commitment to improve the lives of women and contribute to better care and gender health equality. Although it felt right to embark from this position, it also felt rushed and I did not want my intuition to become a rigid worldview; and because my feminist position has a vitality that I cannot crystalise here I chose to stand from an epistemological position that allowed the fluidity that I needed to craft this study. I was beginning to discover something meaningful, to have a felt sense of my views on feminism and gender inequality, feeling the need to remain open to all the possible discoveries.

In recent years there has been much emphasis on the psychological variables involved in the process of chronic pain (from personality traits to cognitive and behavioural factors), and I am sure that these theories have proven to be a great contribution. However, it seems necessary to shift the standpoint of reflection to one that seeks to understand how illness and chronic pain, in particular, unfold in a situated and intersubjective lifeworld, so the *why* of pain can also become a *how*.

As mentioned before, behind my passion for women's health and the existing gaps in the health sciences and care system, there are elements of frustration and anger at the fact that women's symptoms are not being believed or validated. This personal response echoed those of the women of this study. The feelings of frustration and anger can have a creative force, and what I have tried to do is to turn them into a humble exercise of compassion. Gilbert (2017) defines compassion as "a sensitivity to suffering in self and others with a commitment to try to alleviate and prevent it (p. 11)". With this intention in mind, the personal rationale for this study is both simple and ambitiously vast. Regardless of how small my contribution might be, I do hope that it aids to alleviate or prevent some of the suffering experienced by women who live with chronic pain.

In the next chapters I will first provide an overview of the theoretical framework, where I discuss and evaluate the theories that are relevant for this research. Furthermore, I also offer a presentation of the existing empirical literature review, with the aim of identifying the current knowledge and possible gaps in research related to the topic. Following this, I turn to the research methodology, the methodological grounding, as well as the methods used to undertake this research and the rationale for this choice. Next, I present the analysis of the findings, which is followed by the Discussion chapter, where I evaluate the findings and show how they relate to the theory, literature review and research question. Finally, I also present a critical appraisal of the research, as well as its possible contributions.

CHAPTER 2: THEORETICAL FRAMEWORK AND EMPIRICAL LITERATURE REVIEW

Introduction

The purpose of this chapter is to provide a theoretical framework and an empirical literature review. In the first part the theoretical analysis aims to present and develop the existential–phenomenological theories related to the topic of this study, outlining the conceptual approach that I take to answer the research question. The second part, the empirical literature review, explores previous studies that may have attempted to answer the research question of this study and identifies possible gaps, as well as strengths and weaknesses, that this study might help to fill in.

The first part is aimed at familiarising the reader with a theoretical literature review that provides a general insight into the concepts of intersubjectivity and the lived experience of pain. The concept of intersubjectivity was hard to delimit because of its transversality across different disciplines. From its beginning in philosophy, the concept of intersubjectivity has grown in popularity in different fields such as psychoanalysis, infant research, social cognition and neurobiology (Ammaniti & Gallese 2014). It is incontestable that an attempt to explore the concept from all these theoretical models is not only ambitious but also not justified for the purpose of this study. Since it is also not feasible to cover the extensive literature and different phenomenological standpoints on the topic of intersubjectivity, I will cover those that, in my view, seem more relevant for the research. I begin with Husserl's work and his take on intersubjectivity, followed by the contributions of Heidegger, Sartre and Buber.

Given that intersubjectivity is a "relation between embodied creatures" (Zahavi, 2008: 681) and the incumbent role that the body has in perception and projection, the phenomenological concept of the lived-body is also presented in the analysis. Following this, an exploration of the concept of illness from the same framework will be addressed to pave the way for a phenomenological understanding of the experience of chronic pain. In this part of the section I present the contribution of authors such as Geniusas (2020), Morris (2013), Scarry (1985) and Wehrle (2020), to conclude with a more critical appraisal facilitated by Stanier and Miglio (2021). Finally, the last part of the first section is concerned with the relationship between gender and the experience of pain, the first being a social structure that cannot be bracketed from intersubjective experience.

In the second part of this chapter I conduct a literature review to identify empirical research on the topic of my research, as well as identifying the main themes and theories. Moreover, the aim is also to find potential gaps and weaknesses that could be addressed in this study.

While researching existing published literature on the topic of chronic pain and intersubjectivity, I came across a vast amount of information that could potentially have been useful for my study. As a result of the large availability of published research, it became necessary to discriminate between the different types of information that I encountered in order to identify the literature that addressed my research question and spoke to my motivations for researching the topic of chronic pain. Being a novice researcher, the task was not straightforward, and it became difficult not to get side-tracked with data that, although interesting, was not relevant to the research question. For this reason, it was necessary to establish the boundaries of the literature research, which, as aforementioned, was not an easy task, considering the breadth of the existing literature on the topics of pain and intersubjectivity. Once I was able to establish the relevance of the research and the need to answer the research question within a word count, it became clear to me what to consider essential and what to consider peripheral to this research. The second challenge was having to approach the literature with a critical mindset. This meant having to continuously evaluate and analyse the information to become aware of what the literature adds to current knowledge, as well as potential gaps, which is specified in the last part of the section.

A. Theoretical framework

Intersubjectivity: an existential–phenomenological conception

From a phenomenological standpoint, the concept of intersubjectivity cannot be separated from the concept of experience, and it is always applied when trying to determine the self's relation to others (Zahavi, 2001).

The concept of intersubjectivity has its roots in Husserl's phenomenological philosophy and method of enquiry about the experience, which can never be separated from the subject that experiences it. Experience is not just a mental or emotional construct: the nature of experience is mostly transcendental, meaning it is possible to recognise the world and its events as a phenomenon. This means that experience, for Husserl, is inherently intersubjective and that our subjective experiences imply a world beyond ourselves (Thompson, 2005).

Husserl uses the idea of a monad community, where these unities are directed to one other and able to encounter one another. As he writes in his Fifth Meditation (1931/1960):

> Accordingly they belong in truth to a single universal community, which includes me and comprises unitarily all the monads and groups of monads that can be conceived as co-existent. Actually, therefore, there can exist only a single community of monads, the community of all co-existing monads. (p. 140)

The concept of the "lifeworld" employed by Husserl (1989, 1859–1938/1950) represents the means that members of one or more communities or social groups use to structure the world into objects. Each respective lifeworld is responsible for creating a "world horizon" of potential experiences that are expected (to a certain degree) for a member of the group or community at a specific time under given conditions. Thus, the creation of possible worlds and environments becomes possible.

From a phenomenological standpoint, the lifeworld can be conceptualised as the horizon on which we live, act and represent our lives on a daily basis. As such, it is also the world of actions, feelings, affections, evaluation and planning. The lifeworld is fundamentally intersubjective, related to other embodied subjects, as well as being historical and sociocultural. From this perspective, the lifeworld has both a creating and created aspect, in the sense that works as the founding soil of experience but also the universal horizon that constitutes and moderates the everyday world (Thybo Jensen & Moran, 2013; Geniusas, 2020). The lifeworld relies on a system that is implicitly intersubjective, whereby what is considered normal or standard is co-created. In his unpublished manuscript, Husserl states: "My experience as mundane experience (that is already each of my perceptions) does not only entail Others as mundane objects, but also and constantly in existential co-validity as co-subjects, as co-constituting, and both are inseparably intertwined" (Zahavi's translation 1996: 231 of Husserl Ms. C 17 36a, 1973).

Beyond a classic understanding of intersubjectivity as a way of being-in-the-world characterised by intersubjective meaning-making resulting from cultural production, Husserl advocates for a fundamental view of intersubjectivity. Perceptual experience has an intersubjectively accessible nature, meaning that what is perceived exists not only for me but also for everybody else. My experience of phenomena is not private but public as a result of the acknowledgement of a foreign subjectivity that makes the world intersubjectively valid. This is a fundamental aspect of intersubjectivity when it comes to the experience of pain. When the pain sufferer seeks an explanation for the pain experience, he/she objectifies the pain and at the same time seeks for his/her experience to be recognised and legitimised as a thing (Stanier & Miglio, 2021).

Husserl (1989) adopted the term empathy (*Einfuhlung*) from Theodor Lipps and the Munich school as a way to explain an empirical experience where the empathising I experiences the inner life or consciousness of the Other. However, this experience cannot be lived and perceived in inner perception, meaning that I cannot experience others in the same way as they themselves do. This means that it is as a result of this difference that foreign subjectivity is experienced as an Other and therefore foreign (Zahavi, 2001).

For Husserl, it is the experience of the Other's foreignness that allows objectivity; the Other's subjectivity is the necessary condition for real alterity and objective validity. My experience of an object is mediated by my experience of its givenness for Other, the transcendent subject. When as a subject I am capable of realising that my object of experience can also be experienced by others, I can also become aware that there is a difference between the object in itself and its being for me, and that what I perceive is only the appearance of something that exists, not only objectively but also intersubjectively (Zahavi, 1996).

Husserl's idea of encountering others as thematic objects did not satisfy Heidegger (1927/2010), who began with an idea of existence that was already in the world immersed in our environment. We encounter others in a worldly situation; the way we understand one another, and our way of being together, is co-determined by the meanings shaped by the specific situation. For the German philosopher, being born into the world is to be thrown into facticity, born into a given moment in history, a given family and culture. Therefore, our thoughts and actions are undeniably entrenched in these external influences and forces that are beyond our volition. This last aspect differs from a Husserlian approach in the sense that places intersubjectivity in a more situated context.

In *Being and Time*, Heidegger (1927/2010) uses the term *Mitsein* or "being-with", the condition for the possibility of ontically being-with-others. This is the structure of the *Dasein* that is equiprimordial with "being-in-the-world", implying a fundamental form of intersubjectivity, by posing that *Dasein* (human being or human existence) does not exist alone; on the contrary, it is essentially social from the very beginning. From the start, we are related to objects and artefacts (tools, equipment, clothes, utensils, etc.) that make reference to indeterminate others; therefore, *Dasein* is being-with-others regardless of whether or not there is an actual encounter with another.

As well as the term finding ourselves in the world, Heidegger also tells us that we are given over to facticity, meaning-structures that we have not chosen. These meaning-structures are also fundamentally intersubjective, since they are historical and cultural, meaning they are always bound to change between different times and places. From this perspective, if we apply this idea to the experience of pain, we could argue that the intersubjective experience of pain is not just the validation and objectification by an Other, as it could have been for Husserl. In addition, Heidegger would argue that this process of validation is inevitably always tied up with the context.

Heidegger does not conceive *Dasein* as an encapsulated entity; on the contrary, it is, already open to the bodies, expressions and concerns of others in a world of intersubjective meaning-structures. The philosopher's ideas about intersubjectivity were initially accepted by Sartre (1956/1992); however, he thought that the concept of being-with fails to capture the original and fundamental relationship that we have with others. In *Being and Nothingness*, the philosopher distinguishes two main ontological dimensions: the being-in-itself (thingness) and the being-for-itself (consciousness). These ontological dimensions are not only opposed to each other but also unavoidably connected. Later, the author identifies a third dimension, which is the being-for-others, or that who exists in the Other's consciousness. The Other is responsible for the constitution of my being through his/her freedom and subjectivity; therefore, my being-for-itself "must refer to a primary relation between my consciousness and the Other's" (1956/1992, p. 341).

For Sartre (1956/1992), then, being-for-others precedes and originates the being-with-others. This being-for-others only arises through concrete encounters with others. This idea does not imply a return to the empathic approach to intersubjectivity, since Sartre goes further by stating that it is necessary to establish a distinction between the other that I perceive (the other as an object) and the other that perceives me (the other as a subject), and it is in this exercise that I manage to perceive myself as an object for the other that I am able to recognise the other-as-a-subject.

Sartre disagrees with Heidegger's ideas of a relationship with the other that looks more like a "we", instead of consciousness of the "you and me", since the former does not represent knowledge. The author offers a different position of intersubjectivity whereby the encounter between individuals is characterised by conflict and confrontation, as opposed to a peaceful a priori engagement (Zahavi, 2001).

The main idea is that the gaze of the other person has the power to objectify me; I turn into a thing for another consciousness by being looked upon and thereby discover myself as an in-itself, which is yet me. This is an experience that, for Sartre, is primarily characterised by feelings of shame, humiliation and even nausea. To become oneself by way of the direct or indirect gaze of the other appears to be a fundamentally alienating experience: the self is separated from its true essence – freedom as consciousness – in becoming an in-itself (a thing). By defining an intersubjectivity that is not necessarily an inherent and a priori condition of *Dasein*, Sartre (1956/1992), instead, conceptualises intersubjectivity as the encounter with the transcendent *Otherness* that only arises through concrete and factual encounters with others. It is probably what constitutes concrete encounters, and the idea of knowledge between those encounters, that inspired Levinas' (1961/1969) concept of ethics. Levinas, similar to Sartre, states that intersubjectivity is a problem of radical otherness and there is no form of intentionality, including empathy, that will allow us to have access to the experience of the Other; it would not be an Other if that were the case. Intersubjectivity is a process of objectification that only allows us to meet the Other by reducing the Other to an object. In order to avoid a reductionist approach, the author introduces the concepts of justice and injustice, stating that an authentic encounter is first and foremost ethical rather than perceptual or epistemic. These ethics imply that the Other becomes a responsibility to me when he or she questions me and makes ethical demands of me.

An author who made a significant contribution to the relationship with the Other is the Jewish philosopher and theologist, Martin Buber, who in his famous work *"I and Thou"* (1923/1958) introduced the distinction between two basic forms of human relationship: the "I-Thou", the world of relation; and the "I-It", the world of experience. From this perspective, the "I" is twofold in the way that it relates to the world and represents two different attitudes. In the "I-It", according to the author, the relationship loses its actuality, becoming a one-way relationship, whereby the "I" understands and approaches the world as one composed of objects, which can be located in space and time and where there is no distinction between people and things. On the other hand, the "I-Thou" is a two-way relationship based on dialogue, whereby one being encounters another within a mutual awareness. This form of relating is characterised by presence, allowing the encounter and relation to exist.

The present in the I-Thou is not defined by objective temporality: "[The present] exists only in so far as actual presentness, meeting, and relation exist. The present arises only in virtue of the fact that the *Thou* becomes present" (p. 12).

The "I-Thou" relationship lives in the sphere of the "between" (1947/2002), which the author distinguishes from a relationship that has usually been located within the individual or general world, which determines the way that beings relate to one another. The relationship, in his view, takes place in the intersubjective space that is created between the encounter of beings. This encounter, according to Buber (1923/1958), is impossible to capture in an object-oriented language that belongs to the "I-It" attitude because the Thou is not a thing among things. It is for this reason that the author poses that, once the relational event has taken its course in the "I-Thou", the relationship will inevitably become an "I-It", because "it is not possible to live in the bare present. Life would be quite consumed if precautions were not taken to subdue the present speedily and thoroughly" (p. 34).

Therefore, Buber's philosophy poses that there is an ongoing alternation between the two attitudes, with both providing different opportunities to relate to the world and other beings; however, he highlights that "…without It man cannot live. But he who lives with It alone is not a man" (p. 34).

The aspect of the asymmetrical relationship between subject and object proposed by Sartre, and the ethical feature that demands responsibility and concern proposed by Levinas, are aspects that, without a doubt, have important implications for the experience of pain and how it is lived intersubjectively. Similarly, Buber's conception of the I-Thou, and his understanding of how we are directed towards the other instead of being directed towards the world with another, is central when it comes to addressing the way that pain is also lived and borne by others. These ideas will be explored in more detail later in the chapter.

Having explored different perspectives of intersubjectivity within the phenomenological–existential tradition, I will now address the concept of the lived-body, the centre of experience that plays a key role in the way that we encounter other embodied beings in a shared world.

Lived-body and embodiment

The complexity of subjective experience has been acknowledged from the outset of phenomenological thinking. Subjects are inherently embodied creatures who are also embedded in their lifeworld; henceforth, the concept of the lived-body, and its role in intersubjectivity, also need to be considered.

One of the most important contributions of phenomenology to the philosophy of the body has to do with Husserl's (1989) distinction between two different aspects of the body: *Leib,* or the lived-body, which refers to the animated and organic body that is personally experienced; and the *Korper*, the corporeal and purely physical body. The latter refers to a material body, the one that becomes the object of science, as perceived like a physical thing that behaves like an object. The *Leib,* on the other hand, has a much more complex nature, since it is the body that is lived and used to navigate the world, being the home of all subjective and intersubjective experiences.

From this perspective, embodiment is inherently a twofold experience. As Husserl (1989) states: “The same Body which serves me as means for all my perception obstructs me in the perception of itself and is a remarkably imperfectly construed thing” (p. 167).

Embodiment is both the lived and the material; the body is what allows us to perceive and at the same time the subject of perception, an object that can be perceived by oneself but only imperfectly. An embodied subject is, therefore, a simultaneously living-and-felt creature, actively directed towards the world through tactual and visual exploration and, at the same time, able to feel the world, feel the touch and be aware of being seen (Wehrle, 2020).

For Husserl, the world is the result of an intersubjective accomplishment in the sense that it is fundamentally constituted by the encounter of embodied subjectivities, the encounter between the living bodies (Thybo Jensen & Moran, 2013).

Merleau-Ponty, one of the French inheritors of Husserl’s phenomenology, continued to develop the concept of embodiment, which stood out as a notable exception from Western traditions that neglected the body, by suggesting that our existence is neither pure object nor pure subject. Subjectivity is essentially incarnated – we exist embodied; subjectivity is primarily a relation to the world. The embodied self-awareness is what the author conceives as a presentiment of the other and it is because of this incarnated being that I am, that transcends itself, that I am capable of encountering and understanding others who also exist in an incarnated way. The body is an intending entity and, as such, it is through my body that I experience and understand the world. The philosopher’s understanding of the body as the subject, instead of the object of perceptions, aims to overcome the practical and theoretical limitations of the longstanding mind–body dualism (Dreyfus & Dreyfus, 1999).

Contrary to Cartesian thinking, whereby epistemic intentionality is guided by the "I think", thus isolating the self from the world, the lived-body's relationship with the world is characterised by the practical intention of the "I Can". My relationship with the world is through the manipulations of objects in the world through my body (Li, 2015).

By doing this, Merleau-Ponty (1945/2002) distinguishes the lived-body from the objective or physiological body, which does not presuppose the existence of two different bodies; rather, the latter is the objectification of a body that is lived and perceived. I can experience my body as an object of my experience, for example, when I touch my own hand; at the same time, it is through the body and the kinaesthetic and proprioceptive schemas that the experience of the world is possible.

According to Zahavi's (2001) interpretation of Merleau-Ponty, intersubjectivity takes place within an established ontology; the three regions of "self", "other" and "world" belong together. Subjects relate in the world, a world articulated by the relation between subjects; this is what the French philosopher understands as a worldly incarnated existence. In this sense, the self, the body and the world of things and others are not separated from one another but different dimensions of a unique field, as Merleau-Ponty states:

> True reflection presents me to myself not as an idle and inaccessible subjectivity, but as identical with my presence in the world and to others, as I am now realizing it: I am all that I see, I am an intersubjective field, not despite my body and historical situation, but on the contrary, by being this body and this situation, and through them, all the rest. (1945/2002, p. 525)

Our lived experience in relation to the world, according to the author, is not linear or dualistic but rather dialectical, which means that we respond to the world and then the world responds to us in a natural process of interrelatedness. Subjects, therefore, are made through ongoing engagement with others and their environment. This resonates with Weiss' (1999) concept of "intercorporeality", which can be a useful notion to understand intersubjective embodiment, arguing that no form of embodiment is self-identical and discrete. Furthermore, embodiment is never a private experience, since it is always mediated and modified by our continuous interactions and embodied relationships with other bodies, human and non-human.

Also in line with Merleau-Ponty's ideas, Svenaeus (2015) states that the body, which is both my object of experience and what allows me to experience the world, does not show itself to us. The body needs to withdraw in order to open up a focus whereby things in the world can show up to us in meaningful ways. He provides the example of how, when talking to another person, we are not paying attention to the way our bodies feel or move; in this case the body performs silently in the background.

Jean-Paul Sartre (1956/1992) expanded these phenomenological ideas in *Being and Nothingness,* where he distinguishes between three interrelated ontological dimensions of embodiment. The first dimension is the Body-for-Itself, which represents the body that is engaged with the world, a medium for my experience and implicit in the field of action. Sartre puts it that "I exist my body", and it is this lived-body that grounds us in the world, which at the same time aims to transcend.

The second ontological dimension appears when the body is no longer a Body-for-Itself but becomes a Body-for-the-Other. The body is experienced and utilised by the other and is now under the third-person's gaze.

These two categories are exclusive of each other but, at the same time, it is our human reality and part of our ambiguity that makes us combine them. There is movement and an interplay between the transcendent subject and the object for the Other, as Sartre puts it: "Either it [the body] is a thing among other things, or else it is that by which things are revealed to me. But it cannot be both at the same time" (p. 304).

Lastly, he added a third dimension, which is the Body-for-Itself, as known by the Other, which appears with the Other’s look, creating the intersubjective relationship between Myself, who acts, and the Other, who watches.

As well as these ontological distinctions, Sartre also introduces the notion of “flesh”, which represents the “pure contingency of presence” (1956/1992, p. 343), the point of contact with the flesh of another. For this, I need to become “flesh” in order to experience the Other as flesh. Through the notion of flesh and the exploration of intercorporeality, Sartre places special emphasis on the dynamic of tactual and visual relationships between living conscious bodies.

As has been mentioned, phenomenology has always intended to overcome Cartesian dualism. Nevertheless, according to feminist thinking, this dualism has been correlated with the ongoing opposition between the categories of female and male, which were fiercely addressed by de Beauvoir (1972) in *The Second Sex.* Beauvoir’s philosophy of the body was grounded in Merleau-Ponty’s (1945/2002) phenomenological ideas of the lived-body. The author conceived of the body as a lived-body, a field of sensory experience, as well as lived intentionality, that is at the same time encountered by an Other, whose responses mediate our own sense of being. An important contribution from the author has to do with the idea that this lived-body as subject and object is experienced differently by men and women. Her theory describes a subject that is embodied, relational and situated.

The body is fundamental when it comes to understanding the life of a person, in the sense that the world is experienced through one’s body, which represents both possibility and limitation. From this perspective, the female body situates women in a context characterised by a lack of freedom and oppression. The female body, according to the author, has been subjected to social structures imposed by the Other, finding herself in a place of oppression and alienation throughout her life. Following this line of thought, the female body as a situation is therefore in a different situation to the male body. The male embodied experience is the norm against which the female-embodied identifies, and, instead of transcendence, the author states that the female body is submitted into immanence, a state of subjection and stagnation, and “rather than looking purposively to the future, life goes continuously in circles” (Kvigne & Kirkevold, 2002: 84).

In *Throwing Like a Girl* Iris Marion Young (2005) draws upon Merleau-Ponty and de Beauvoir's theories in order to expand the ideas of immanence and objectification. In a patriarchal society the autonomy, subjectivity and transcendence that are denied to women are mirrored in her body and her motility. As such, the author states that feminine movements are characterised by inhibited intentionality, ambiguous transcendence and discontinuous unity with her surroundings. She writes:

> Women often approach a physical engagement with things with timidity, uncertainty, and hesitancy. Typically, we lack an entire trust in our bodies to carry us to our aims. We often experience our bodies as a fragile encumbrance, rather than the medium for the enactment of our aims. (p. 34)

The author argues that it is possible to get some understanding of the way that gendered differences take place in our society by looking at the way that women and men embody their bodies: the way they move, take up space and the different ways that they inhabit their bodies. She goes further, stating that, as women living in a sexist and patriarchal society, we are “physically handicapped” (p. 42), our bodies objectified, confined and inhibited. The possibility of inhabiting and mastering a world whereby our intentions and projections are responsible for transcendence is inhibited and arrested.

Having argued for the relevance of the lived-body in the phenomenological tradition, the next section will explore the experience of illness within the same framework.

Illness: an existential–phenomenological approach

According to Csordas (1999), embodiment is an existential condition whereby the body is the intersubjective ground of experience. This conceptualisation assumes that, when studying the body, we are not studying the body per se but the culture and experience, which can only be understood from a position of bodily being-in-the-world.

In the *Zollikon Seminars* Heidegger (1987/2001) states that *Dasein,* or human existence, cannot be reduced to measurements and the human being cannot be treated as a physical organism determined by causal laws. The methodologies used by natural sciences are not able to account for the experience of illness and how the latter disrupts and alters the way that we interpret ourselves and the personal meanings of the illness. The philosopher argues that it was necessary to situate the sufferers within their lifeworld, in order to attend to their individual and unique meanings assigned to their illness.

Heidegger states that natural sciences fail to contextualise existence, regarding individuals as objects, which in turn continues to reinforce a dualism between the objective –the measurable truths – and the subjective – the meanings that we assign to experience within a sociocultural and personal context.

These ideas were later developed by Medard Boss, a Swiss psychoanalytic psychiatrist, friend and pupil of Heidegger, in *Existential Foundations of Medicine and Psychology* (1979), whereby he dissolves the existing dualism between somatic and psychiatric illness. For the author, the experience that a subject has of his/her illness, whether physical or mental, is always already shaped and mediated by his/her “being-in-the-world”. Boss’ writing helped to address the wider audiences with the fact that, despite all the advances in science and medicine, the unique pain of being human is invariably bound up with the human condition itself.

An existential–phenomenological approach to health and illness stands as an alternative to the current dominant paradigm of natural sciences, which assumes, first, that all phenomena are reducible to physical elements that can be measured, and, second, that these elements can be explained by causal laws of nature (Aho, 2018). In contrast with the latter, an existential approach begins from the first-person perspective, from its phenomenological roots; the aim is to reach an understanding of the experience by returning to “the things themselves”, to the experience as it is lived by the individual.

Drawing upon Merleau-Ponty’s concept of the lived-body (1945/2002), Bullington (2013) argues that the natural sciences have taught us to understand ill health as an objective physiological process that occurs in a material body. Words such as “tumours”, “headaches”, and “back pain” transport us to the realm of the objective body, whereby we witness a physiological process that takes place in an impersonal, objectified body.

The experience of illness, according to the author, can only be found in the lived, the “in-between” space of the individual's relationship to their world.

Taking the example of medical aetiology and diagnosis, both Aho (2018) and Bullington (2013) agree that, by objectifying the body, there is a dismissal of the lived experience and the personal meanings assigned to the illness. The objective body, therefore, admits a level of causation such as a fracture that causes pain or a virus that causes the flu, which does not apply to the experience of the lived-body and which cannot be causally determined in the physical world. Health and illness are concepts that can only be understood from the ambiguous, embodied and intertwined subjectivity of existence.

The latter chimes with Christophy’s (2017) study on unexplained physical pain, which confirms that attempts to medicalise the experience of pain reduced the patient’s opportunities to create meaningful personal narratives that could have a significant impact on their recovery. This impersonal, and therefore objectifying, treatment of the experience of pain ended up erasing the person-in-pain.

When it comes to objectifying the body, Buber (1923/1958) argues that medicine and science have benefited from the “I-It” attitude, in the sense that this form of relationship allows the development and accumulation of knowledge and the scientific order of nature. In this sense, the “I-It” is essential to living in the world, with the caveat that this scientific understanding should be in the service of the “I-Thou”, “…the truth of relation which is above the understanding and gathers it up in itself" (p. 42).

According to Scott et al. (2009), it is possible to say that many clinician–patient relationships are characterised exclusively by experiencing and using; diagnosis and treatment are to be seen as the main endeavour. From this perspective, the Other can never become an "I-Thou" and the medical encounter represents a form of "I-It" relationship that has the potential to be dangerous, since it may overlook the relevance of the "I-Thou" in the process of meaning-making and understanding what it means to be human. Therefore, the authors highlight that a scientific medical effort that fails to connect with the relational foundations of what gives meaning to a particular experience is not only a sterile but also a potentially harmful exercise.

As opposed to patients' experiences with orthodox medicine, complementary medicine offers an approach that may provide an opportunity for "I-Thou" encounters, as evidenced by Cartwright and Torr (2005). According to the authors, complementary medicine is characterised by a psychotherapeutic quality that offers reassurance and social support through an active and open act of intimate listening.

Through the experience of a healthy body, we tend to disappear in the ongoing flow of our existence and our bodies tend to withdraw from awareness. Conversely, in the experience of illness, the physical and perceptual functions that used to mediate our experience in the background are disrupted, and the body comes to our awareness as an object. The latter is expressed in Gadamer (1996): "Illness can make us insistently aware of our bodily nature by creating a disturbance in something which normally in its very freedom, almost completely escapes our attention" (p. 73).

In this sense, the experience of illness reveals a world that is threatening and unfamiliar, disrupting what once felt like an implicit sense of connection and familiarity with the world.

Drawing on Heideggerian ideas, Aho (2018) states that the individual who experiences a healthy body is, therefore, a "they-self" (*Man-selbst)*, blending and disappearing into the relational flow of social practices, constituting his or her identity. In illness, this relational flow is disrupted, and the individual who is ill becomes an object bound to be judged by others for breaking the synchronised flow of the “being-there-with-others” (*Mit-dasein).* It seems relevant to mention the concept of “mineness”, or what Heidegger (1927/2010) calls *Jemeinigkeit,* when speaking about embodiment, since this entails that the body is not something identical to the ego or the “I” but instead something that is experienced as “mine”. Following this line of thought, extreme experiences felt in the body, which could be experienced as intrusion, such as serious illness, can have an impact on one’s sense of self (Thybo Jensen & Moran, 2013).

A further elaboration of Heidegger’s ideas can be found in Svenaeus (2001), who states that, as human beings, or *Dasein,* we are constantly between the “being-at-home”, understood as the dwelling with the familiar, and the “not-being-at-home”, the encountering with the uncanny. Health is a way of being-in-the-world whereby the “being-at-home” prevents the “not-being” at home from becoming apparent. In illness, the “not being-at-home” is “brought to attention and transformed into a pervasive homelessness” (p. 8).

Not only is the unhomelikeness of illness – as the author states – pervasive but it also takes control of the being-in-the-world, and the attunement is one of helplessness, resistance, despair and disorientation.

In his definition of health American sociologist Talcott Parsons (2010) agrees with what has been mentioned. The author, drawing upon phenomenological ideas (Jules-Rosette, 1980), defines health as: “The state of the optimum capacity of an individual for the effective performance of the roles and tasks for which he has been socialised. It is thus defined with reference to the individual’s participation in the social system” (2010: 274).

From this perspective, the author states, illness is a socially institutionalised role type, which he calls the “sick-role”, with attributed generalised disruptions to the individual’s capacity to perform his/her specific role. Illness then, according to Parsons, is a form of deviant behaviour within society, whereby the subject becomes excluded from social obligations and sanctioned by society. Those in the "sick-role" have the responsibility to seek recovery; likewise, the aim of the medical profession is to return the individual to conventional social roles.

Following this analysis of illness from a phenomenological and existential standpoint, the next section provides a more detailed and specific analysis of the phenomenology of chronic pain.

The phenomenological experience of pain

Taking into account Husserl's idea of embodiment, it is possible to say that pain is neither purely physical nor purely psychological. Pain instead can be understood, under phenomenological thinking, as an experience that affects the lived-body, an embodied feeling that is lived through embodied consciousness. From this perspective, pain should not be conceived within the realms of a physiological body or a disembodied consciousness but from the *Leib,* the animated body, the body that *I am.*

Following Husserlian tradition, Geniusas (2020) states that pain is a form of protest from the lived-body against his/her own will and an expression of his/her spirit, whereby the lived-body's experience of free movement becomes frozen. The body in pain, therefore, aims to become the single object from which I cannot distance myself. From a Heideggerian (1927/2010) perspective, the experience of pain is to the lived-body not a *Zuhandenheit* or "readiness-to-hand" but an "unreadiness-to-the-hand", no longer a servant of the will. The body becomes a presence, noticeable in its own malfunction.

Conceiving pain from the viewpoint of the lived-body, and that pain is not merely a somatic or a psychic experience, in *The Phenomenology of Pain* Geniusas (2020) distinguishes four different ruptures that are experienced by the lived-body in the experience of chronic pain. **First**, chronic pain disrupts the normal relation between the self and the body: when pain presents as an imperative, the body no longer obeys the self. Like thirst or hunger, pain presents as a command aimed at protecting the injured body, but in chronic pain it behaves like a “resounding message, which the intended recipients either do not acknowledge as a message or fail to understand” (p. 187). There is a paradox in the sense that the body in pain is simultaneously experienced as being my own body but, at the same time, the body has become something alien that no longer responds to the self.

As has been established, pain is not just an assault on the body but also an assault on the self, and this refers to the **second** disruption identified by Geniusas: the person’s self-relation. By no longer being able to achieve most of the basic activities, the pain-bearer loses self-reliance and self-confidence. The author states that pain is not merely a sensation but also a form of attunement or mood that is experienced through our bodies. It is through these embodied moods that the world acquires meaning, and when the pain becomes the omnipresent mood the world begins to disappear. The horizons for meaning-making begin to shrink until there is nothing else but pain; the world becomes poor of meaning when the pain sufferer cannot endure this imperative demand of pain to become the focus of the world of experience.

Third, chronic pain disrupts the perceptual, affective and conceptual relationship between the subject and the world. Pain is the wall, the obstacle between the self and his/her surroundings, which are now inaccessible and unreachable. The body in pain becomes the single object of attention.

Finally, the **fourth** disruption refers to the fact that chronic pain alters the person’s relation with others. The author identifies three aspects of this disruption: first, pain, being a non-shareable experience, creates a breach between the subject in pain and the other. The second aspect has to do with the fact that pain exists at the limits of understanding, which will inevitably have an impact on pain’s credibility and legitimacy. The person who suffers from chronic pain will inevitably become dependent upon others, hence creating an asymmetrical relation.

In addition to the previous analysis, Morris (2013) also engaged in the phenomenological analysis of chronic pain, distinguishing three main relevant themes. The **first** is concerned with the idea that chronic pain disrupts the lived world, experiencing an encompassing unmaking of the world of the sufferer, who at the same time will endeavour to remake it.

Second, following Garro's (1992) ideas, illnesses such as chronic pain have the power to transform the relationships of the lived-body. Instead of behaving like a united entity, the self and the body no longer act as one, with the lived-body reduced to the object-body. Drawing on Merleau-Ponty's ideas of embodiment, Morris states that this aspect has a profound impact on the field of intersubjectivity. In a state of health, "my perspective of the world...slips spontaneously into the other's" (Merleau-Ponty 1945/ 2002: 411). For the pain-bearer, though, his/her reality no longer slips into the world, beginning to inhabit a different world, where body reciprocity and mutual understanding are no longer there. The last and **third dimension** identified by Morris is the observation that the authenticity of the experience of pain will – at some point – be questioned by others. There is a pervasive distrust that slowly creates deep feelings of alienation.

The distrust and lack of credibility that pain entails, as stated by Geniusas and Morris, could be the result of the liminality of pain, as Jackson (2005) proposes. Pain transgresses the dualistic division between body and mind, inhabiting a transitional place of ambiguous order that resists categorisation and therefore understanding. This liminality means that chronic pain sufferers are moved between different classificatory spaces, needing both medical and psychological treatment. The author also proposes that the pain sufferers occupy a morally liminal space when having to legitimate their entitlement to help. This help can take different forms and can include medical, financial and pharmacological aid.

The transgression of the Cartesian division that pain poses creates an ambiguity that "turns sufferers into quintessentially liminal figures, vulnerable to the stigmatization" (Jackson, 2005:

346). The stigmatisation suffered by subjects with chronic pain is related, first of all, to the inappropriateness of pain behaviour. The unending nature of chronic pain, as well as the psychologisation of the pain experience, result in external delegitimisation of the illness as such, attributing responsibility for it to the sufferer. Second, stigmatisation occurs as a result of the disruptive aspect of chronic pain and the costs implied in the disability, such as abuse of the healthcare system, loss of productivity and never-ending disability payments.

As well as the previous analysis, it seems relevant to include Scarry's (1985) analysis of pain. One of the main contributions of the author is concerned with the social phenomenology of pain and its intersubjective nature. Drawing upon the analysis of the experience of pain in torture, the author concludes that pain, even when not inflicted by another, as in the case of torture, retains the elements of subordination. Although not explicit, authority is still present and leads to the seeking of responsibility and the need for interpretation. Power is attributed to the source of the pain, and when this cannot be identified, power is transferred to another, who can provide a narrative and therefore treatment.

Furthermore, pain obliterates the contents of consciousness, becoming a totality. What started as an uncomfortable limited internal sensation becomes an encompassing experience that not only occupies the entire body but also transcends it.

Although universal in nature, pain has neither the facial expression to convey it nor the language to express it. Pain's nature is both common and unfathomable. According to the author, words will never be enough, and we are constantly failing when it comes to trying to communicate it or to fully grasp it in others when being communicated: "Because the existing vocabulary for pain contains only a small handful of adjectives, one passes through direct descriptions very quickly and almost immediately encounters an 'as if' structure. It feels as if…; it is as though" (p. 15). Finally, pain resists language and therefore objectification. Pain that is not accompanied by a visible physical injury or a specific diagnosis can only increase pain's annihilating power in the lack of recognition and acknowledgement from others.

One last aspect of this phenomenological analysis of the lived-body in pain is concerned with the temporality of the pain experience. Husserl (1928/1991) established a distinction between the inner, or subjective, time and the objective, or outer, time. In contrast with objective time, which is inflexible and rigid, subjective temporality is the lived time and is not externally restricted. In the experience of chronic pain, the latter is experienced as a disturbance in which lived duration cannot be measured in relation to objective time, since chronic pain obliterates the ordinary experience of time (Morris, 2010). Furthermore, for those who suffer from chronic pain, temporality is lived "as infinite sameness that is cut adrift from other temporal fields" (Geniusas, 2020: 111). Pain, with its depersonalising nature, annihilates the personal past, as well as the personal future; it additionally imprisons and forces the subject into the realms of presence, which is felt disconnected from other temporal realities.

Wehrle (2020) states that in the experience of intense pain, we lose our directedness towards the world and our bodies become the object of intentionality, an alienating situation where the sense of time and space is lost. The subject in pain cannot experience change on the level of internal time and at the same time cannot refer to his or her body as a temporal object. Drawing on Scarry's (1985) ideas, Wehrle states that, intersubjectively, the pain-bearer loses "all sense of an objective or intersubjectively-shared time" (p. 517).

Influenced by Husserl's philosophy of embodiment and the concept of the lived-body and empathy, Stanier and Miglio (2021) take issue with Scarry's notion of pain as something that represents radical alterity, rendering it an exclusively private and non-shareable experience. When objectifying the pain, the subject seeks to find an explanation for this experience, which leads him/her to "seek recognition and legitimation of the pain as some thing" (p. 109). The authors argue that pain can be shared and recognised in an intersubjective encounter, and through the exercise of empathy we can experience others' pain.

The authors go further, stating that pain is also a co-experienced phenomenon, giving the example of friends or family members who can “know” what it is like to live with pain, and their responses will have an impact on the way that the pain is experienced by the subject. It is the same with the doctor, whose capacity to validate or invalidate the pain of the patient will have a considerable impact on how pain is lived henceforth. It makes sense then that from this standpoint, the authors argue that, from an intersubjective experience, subjects in pain are produced and sustained by social and political contexts, making pain a constitutive aspect of subjectivity. Similar to the authors, Fullarton (n.d) also argues for an understanding of pain that conceives of it as a shared experience rather than a private one. Being fundamentally intersubjective, pain is both affected and conditioned by interpersonal relationships.

Given the bearing of social, cultural and political aspects in the experience of pain, the final section of the first part is concerned with gender as a social structure and its relevance when it comes to addressing the experience of chronic pain.

Female lived-body and the experience of illness

There is evidence that medical research and practice have, for a long time, assumed a narrow view of what the “normal” human body should be like, which in turn has compromised the care of anyone who does not fit into this category. From this perspective, sociodemographic aspects such as race, ethnicity, gender, culture and sexual orientation are important determinants of health and can have a significant impact on health outcomes (Krishnan et al., 2019).

From a feminist perspective, Kvigne and Kirkevold (2002) state that illness and physical changes must be conceptualised from a gender perspective. The body, conceived as the lived-body, must be understood not only as a biological reality but also as a socially and historical entity. Furthermore, following de Beauvoir’s (1972) feminist thinking, the body is fundamental when it comes to understanding the life of a woman, since subjectivity is developed and the world is conquered through one’s body. But when it comes to medical science and the study of illness, the male body has become the default human construction (Kvigne & Kirkevold, 2002). de Beauvoir’s ideas are key when it comes to challenging the hegemonic male discourse: "Representation of the world, like the world itself, is the work of men; they describe it from their own point of view, which they confuse with absolute truth” (1972, p. 161).

Women have been measured against the norm of men, the essential human subjects, and any biological deviation from this standard renders women biologically inferior. This dominant medical and scientific discourse has, for centuries, confirmed the pathology of women’s bodies and subjugated women to prescribed activities, clothes and behaviours deemed appropriate to them (King, 2004).

This is in line with Foucault’s (1963) theory, which states that medicine has historically gained significant power to define reality by controlling advantaged and respected scientific knowledge. It is this knowledge that came to define the boundaries of what normality and deviance mean. In the same way, medicine has become an institutional regulation, which, through its discourse, has objectified our bodies through acts of surveillance, control and manipulation.

Male dominance, and with this, the assumption of the superiority of the male body was paved into medicine’s early foundations in ancient Greece. In the third century BCE, Aristoteles described the female body as an inverted version of the male’s, whereby women’s genitalia were turned outside in. This assumption deemed women medically faulty, deficient, and defective. On the other hand, women’s possession of a uterus defined their purpose which was to reproduce hence, being a woman was reduced to the “female sex”; she was her biology, was ruled and governed by it. Since then, most women’s illnesses were reduced to the mystery of their reproductive organs, and the uterus was to blame for all the possible disorders and dysfunctions of both body and mind (Cleghorn, 2021).

Many of these illnesses of the womb that affected women were grouped under the label "hysteria", a disease that has been widely recognised by Western medicine. Although the condition was initially associated with the womb, Freud and other contemporaries popularised the idea that hysteria was all in the mind. The widespread idea that women are inherently irrational and filled with uncontrollable emotions has, over a long time during human history, justified women's subordination (Jackson, 2019).

The biological essentialism and deterministic paradigm which defines women according to their reproductive physiology meant that since mid-nineteenth century, women's lives have been increasingly medicalised, and more female conditions have been identified, connoting the deviation from what is considered the normal (male) standard. From this point of view, "gender is a pervasive and powerful method of social control that both produces and restricts one's mode of being" (King, 2004, p. 36).

In sociological and feminist research, gender and illness have been viewed as not merely something we "are" or "get" but as social practices that we "do" or "express" in social encounters (Werner & Malterud, 2003). For Butler (1990), the body is always interpreted through social and cultural meanings; the body does not have an a priori meaning before the mark of their gender. Gender is not the expression of an authentic core but the effect of our performances, which are fabricated through imitation and gradual assumption of cultural idioms.

The stereotypes and biases associated with the binary genders are expressed in provider–practitioner interactions and have a negative impact on both women and men. Gender norms associated with masculinity, for example, make it difficult for men to make use of healthcare or express feelings of physical or mental vulnerability. An important part of this discrimination takes place on an unconscious level and reflects the underlying sociocultural values of the patient and the healthcare practitioner (Govender & Penn-Kekana, 2008).

Vlassoff’s (2007) research offers evidence that gender has a significant effect on the causes and determinants of non-communicable diseases and conditions in both developing and developed countries. The author poses that those sexual biological differences do not in themselves explain health behaviour and health outcomes. Rather, health and illness also need to be understood in terms of social and economic factors, which are in turn influenced by cultural and political views in society. From this point of view, gender analysis is an important variable that needs to be included in the study of health and illness.

In recent decades important research has been conducted on the topic of pain and gender differences. For example, Ramírez-Maestre and Esteve (2014) found that women are more sensitive than men to threat-related stimuli and that this generally leads to an increased pain perception. The same study highlighted the fact that gender roles have been associated with the socially expected pain response, in the sense that masculine gender norms dictate increased tolerance of pain among men, while feminine gender norms determine the acceptance of pain as a normal part of life, being more permissive of pain expression.

These stereotypes respond to the expectations that the normative masculine body is more likely to ignore the pain and follow its desires, while the feminine body places more emphasis on ignoring those desires while being more sensitive to its physical and emotional pain, and being encouraged to react to and emphasise those experiences. It is because of this precise discourse of embodied masculine subjecthood and embodied feminine objecthood that the dynamics between power and gender are continuously created and reinforced (Mason, 2018).

However, in the case of women it is not only the gender factor that has been overlooked in medical research and practice but also the sex and biological differences. The dearth of knowledge about women’s bodies has led medicine to fail to offer adequate care. This could be because, historically, women have been excluded from medical trials, resulting in medical knowledge and care, which has been mostly centred on male physiology. As well as gender, sex is an important factor when it comes to physiology and disease because of the genetic, epigenetic and hormonal elements at play (Mauvais-Jarvis et al., 2020).

Following this line of thought, Criado-Perez (2019) states that, because female bodies have not been given the same level of medical attention as male bodies (the latter being considered the default human), women's physical pain is far more likely to be labelled "psychosomatic" or "emotional", resulting in many pain conditions being left undiagnosed and untreated.

The relationship between pain and gender within these power structures – our societies – appears to be complex and controversial. Chronic primary pain in women represents, in many cases, a type of unexplained medical diagnosis, and this enigmatic conclusion carries particular meanings and repercussions, not only for the patient but also for those around, who are immersed in the power dynamics that the medical discourse generates.

The first part of this chapter was aimed at presenting and analysing the main concepts and notions that are considered necessary to address the intersubjective experience of chronic primary pain in women. In the next section, the literature search, I turn to the empirical data on the topic.

B. Empirical literature review

Introduction

As well as a theoretical review, I also conducted a systematic literature search in order to identify published, scholarly, empirical articles relevant to the research question. The purpose of this section is to systematically review the findings of qualitative studies that have addressed women's experience of chronic pain. Qualitative research methodologies allow the experiences to present in a more in-depth fashion, thus enabling rich accounts of what it is like to live with chronic pain. For the purpose of this study, I have chosen published research that used qualitative methodologies, as well as phenomenological methods. These criteria were selected to systematically review the findings of phenomenological investigations of the intersubjective experience of pain to become familiar with current research, find out what has already been done and identify possible gaps or under-researched themes in the topic.

There is currently a large corpus of research studies in psychology that aim to describe the lived experience of illness, and several of these studies are on the experience of pain (Smith & Osborn, 2015). The efforts to understand the lived experience of pain come in response to compensating for the lack of recognition of personal meaning within a personal and social context. It is expected then that by exploring patients' subjectivity, a further insight will be gained regarding the specific needs of this group, thereby informing both practice and research (Snelgrove & Liossi, 2009).

The literature review did not identify specific empirical studies on the experience of intersubjective chronic primary pain in women. This could be explained by the fact that, first, chronic primary pain is a recent diagnostic category that was only adopted during the 72nd session of the World Health Assembly in 2019. Second, the concept of intersubjectivity, as a fundamental aspect of the lived experience, was not evidenced in the literature review; no previous studies were identified on the intersubjective experience or intersubjectivity as such. In spite of the lack of specific empirical literature that could potentially help to answer the research question, phenomenological research studies on chronic pain in women (such as fibromyalgia, migraine, endometriosis, pelvic girdle pain, vaginismus, irritable bowel syndrome and vulvodynia) were identified and reviewed with the aim of identifying related and relevant knowledge.

Thematic literature analysis

With the above in mind, the following online databases were searched: EBSCO Host (PsycINFO, Education Research Complete, MEDLINE, PsycARTICLES), Google Scholar and

Ethos. Search strategies entered into databases were: “chronic pain”, “pain”, “fibromyalgia”, “lived experience”, “endometriosis”, “migraine”, “vulvodynia” “intersubjective” and “women”.

The inclusion criteria for papers were the utilisation of qualitative methods, phenomenological analysis of women’s experience of chronic pain, and obtainment of the full text published in the English language. The exclusion criteria for papers and published dissertations were: non-qualitative, non-women, non-phenomenological, non-English language and non-chronic pain.

A total of 23 research papers (Appendix 1) were selected, analysed and structured in a thematic literature review to create meaningful constructions. A phenomenological approach to the analysis as proposed by Randolph (2007) was used to conduct the literature review, this was done following the four steps proposed by the author:

Step 1: Bracketing. As a researcher, I “bracketed” my experience with the phenomenon of study by stating my own position regarding the phenomenon of chronic primary pain in the reflexivity section.

Step 2: Collect the data. I read the selected studies that could help me answer the research question.

Step 3: Identifying meaningful statements. I highlighted empirical claims made about the experience of chronic pain and made notes of these findings on a table.

Step 4: Giving meaning. Once the meaningful claims were identified, I wrote the keywords/themes next to them in a different column. A list of thematic words was created and grouped under general categories, which provided the first outline of the thematic review. After this, I re-read the literature, trying to notice things that I might have missed during the first reading.

Step 5: Thick, rich description. This final step consisted of creating thick and rich descriptions of the essence of the phenomenon as it was described in the existing literature review. With the main categories outlined, I grouped them into three overarching themes and began to draft the main body paragraphs. All the associated keywords/themes were listed under the overarching themes so that I could relate them to the specific source for the analysis.

Theme 1 – The need to feel acknowledged

Theme 2 – From powerlessness to adjustment

Theme 3 – Identity and social roles

Theme 1 – The need to feel acknowledged

Several studies have revealed that women with chronic pain are generally met with disbelief and doubt about their symptoms. Numerous authors have reported that women with chronic pain have experienced patriarchal attitudes such as patronising dismissal of their experience in the healthcare system, and in many cases their chronic pain was attributed to a psychological or emotional cause (Clark, 2012; Juuso et al., 2014; Söderberg et al., 1999; Warwick et al., 2004; Sturge-Jacobs, 2002; Shaefer, 2017) or female "neuroticism" (Shallcross et al., 2018). The lack of legitimisation makes it difficult for women to assert themselves because of the associated fear of being labelled with a psychological diagnosis (Shallcross et al., 2018). This is also evidenced in Werner and Materud's (2003) study, whereby women have reported negative experiences during medical encounters such as feeling questioned and judged, not believed and seen as suffering from an imaginary illness, in some cases being given a psychiatric label, as well as assigning psychological models to understand their pain.

It was also reported in the literature that women have been told that their pain was exaggerated or imagined and the pain was attributed to their low pain thresholds (Grundström et al., 2018). In the case of endometriosis, the pain was normalised as period pains and, as a result, the women were made to feel that they should be capable of coping with a pain that is common during menstruation (Clark, 2012).

In many cases the lack of objective tests and of observable physical abnormalities compounded the attitude of disbelief and dismissal on the part of healthcare professionals, making the women feel belittled, discredited and that they were not being taken seriously or their credibility was being questioned (Juuso et al., 2014; Grundström et al., 2018; Shallcross et al., 2018; Sturge-Jacobs, 2002; Osborne, 2008; McCann, 2015).

The lack of credibility experienced by women was not only evident in the healthcare settings, since feeling questioned when it came to the reality of their illness and pain was also experienced within their families and social settings. The literature shows that there is a strong link between the assumption of chronic pain being an invisible condition and the attitudes of disbelief and dismissal (Werner & Malterud, 2003; Arman et al., 2020). Having to deal with an invisible disability adds to the anxiety and frustration of women, especially when having to face the dilemma of how well they look compared to how unwell they feel, which is a source of conflict not only for themselves but also with their physicians, family members, friends and employers (Sturge-Jacobs, 2002). Other studies (Rutberg & Öhrling, 2012; Palacios-Ceña et al., 2017) have shown that by suffering from an invisible pain condition such as migraine, women have felt constantly doubted and had a deep need for recognition and to be believed; in some cases they felt ashamed for seeking medical help for a condition that is not only invisible but also a barely recognised disease.

The frustrations of having an invisible condition such as fibromyalgia have also been explored in prior studies (Söderberg et al., 1999; Juuso et al., 2011, 2014), which found that women were met with distrust because of the invisibility of the illness despite the body changes they were experiencing. Their bodies were in pain most of the time but it was an invisible bodily feeling, which made them feel constantly questioned. Studies on endometriosis and fibromyalgia (Grundström et al., 2018; Juuso et al., 2011) found that the fact that women had to continue with housekeeping chores, despite the pain, also contributed to not being taken seriously.

Some authors (Wuytack & Miller, 2011) have suggested that the feelings of sadness and frustration created by this invisibility of pain, and the resulting experience of feeling questioned or not listened to, led women not to communicate about their illness in order to avoid misunderstandings and unwanted reactions. Fear of being judged as silly, lazy or stupid was seen as an obstacle when it came to sharing their experience of pain, as evidenced in Juuso et al. (2011). The relationship between unexplained and/or invisible illnesses and shame has been reported in several studies, such as Werner and Malterud (2003), who found that when women who suffered from chronic pain were not believed or taken seriously, their honour, integrity and human dignity were affected. Consequently, shame was experienced when women felt guilty about their non-functioning bodies. When their bodies were compared and unable to fit into what is seen as normal, the women felt rejected, ridiculed and disregarded.

Delays to diagnosis across conditions have frequently been reported in the literature; Clark's (2012) findings revealed that, in the case of endometriosis, the average length of time taken to receive a diagnosis was 12 years. Similar findings of delays in diagnosis and appropriate referrals have also been evidenced in the case of vaginismus (Johnston, 2013), migraine (Palacios-Ceña et al., 2017), vulvodynia (Shallcross et al., 2018) and fibromyalgia (Juuso et al., 2014). Several studies found women reporting that delays in diagnosis are usually attributed to a lack of knowledge about certain conditions such as fibromyalgia (Juuso et al., 2014) and pelvic girdle pain (Engeset et al., 2014). For instance, Grundström et al.'s (2018) study evidences that women who suffer from endometriosis are usually met with ignorance by healthcare professionals, which leaves them feeling hopeless about their health and future. And, as Shaefer's (2017) study demonstrates, the ignorance about certain conditions is not confined to clinicians but is also found among the general public, and there is a lack of awareness about certain conditions, such as IBS.

On this basis, it is not surprising that women across different studies and conditions report that their journey to a diagnosis was perceived as a battle, a fight, a quest and a long tortuous process (Palacios-Ceña et al. 2017; Sturge-Jacobs, 2002; Clark, 2012). The journey towards a diagnosis, and repetitive and futile encounters with healthcare professionals, were reported as psychologically harmful, resulting in anxiety, depression and psychosexual difficulties (Shallcross et al., 2018).

For instance, Werner and Malterud (2003) found that patients with fibromyalgia referred to their encounters with healthcare practitioners as a legal battle where they had to prove and show evidence, as if it were a court case: "The question is, will the woman patient be allowed to witness her own case, will she be believed or will she be sentenced to treatment by a psychologist, or will her case (i.e. symptoms) be dropped?" (p. 1414).

Receiving a diagnosis was reported by most women as a relief (McCann, 2015; Sturge Jacobs, 2002; Söderberg et al., 1999). For some, having a diagnosis helped them to find the vocabulary to communicate with their friends and family about their experience of pain, which alleviated their feelings of shame and fear of rejection (Shallcross et al., 2018). This is related to the fact that feeling misunderstood is also associated with the obstacles encountered when having to talk about their pain; sometimes trying to explain how they feel to others takes more energy than saying nothing about it (Juuso et al., 2011; Shaefer, 2017).

A number of authors have recognised the importance of feeling acknowledged and legitimised in their experience of pain, which translates into being believed and taken seriously (Juuso et al., 2011, 2014). As Råheim and Håland (2006) suggest in their study, from a phenomenological standpoint, physicians must be able to transcend the one-dimensional aspect of traditional medical knowledge. Acknowledgement means, for the authors, the capacity to recognise the lived experience of the other and acknowledge one's role as a fellow human being.

Theme 2 – From powerlessness to adjustment

Several studies have revealed that the nature of chronic pain is felt like a relentless and inescapable presence that inundates women's whole existence (Gutke et al., 2018; Sturge-Jacobs, 2002; Juuso et al., 2011) and a continuous tortuous pain (Ramsey, 2012). As most studies agree, the unrelenting pain is also overwhelming, with the women feeling exhausted by the ongoing struggle against pain and at the same time despairing about the future. And, in addition to the pain, Schneider and Fletcher (2008) identified that symptoms such as fatigue were equally consuming.

Similarly, it has been found that, when in pain, the women felt as if their bodies had been taken over by it, which was experienced as something alien, intrusive, an enemy that is almost impossible to control or escape from. Authors such as Råheim and Håland (2006), who situate the experience of pain as occurring in the lived world, refer to this alienation as the disintegration between the self and the body and the latter with the practical world.

One of the main aspects of their conditions, reported in the literature, was related to their feelings of powerlessness in the face of their pain, an uncontrollable event that had a profound impact on their lives. Several studies revealed that the feelings of powerlessness were usually accompanied by feelings of resignation, emptiness and feeling defeated (Juuso et al., 2011, 2014; Osborne, 2008; Johnston, 2013).

One of the aspects of pain that can be related to the feelings of powerlessness has to do with what has been evidenced in numerous studies as the lack of control and unpredictability of the pain. Often, in the case of fibromyalgia and other conditions, pain and associated symptoms present unannounced and with no specific trigger. This can lead to an enormous amount of uncertainty and makes the management of the symptoms extremely challenging (Juuso et al., 2016). In an effort to compensate for the unpredictability and powerlessness related to their pain, it has been evidenced that women continuously aim to attain control of their symptoms, trying to get ahead of flare-ups, acute cramps or migraine attacks. By wanting to regain control over their bodies and identify possible triggers, the women are constantly trying to outsmart their pain episodes. This means, as demonstrated by Ramsey (2012), that because of the unpredictability of migraine episodes, women who suffer from it tend to live their lives constantly on guard or in a constant state of "readiness" (Rutberg & Öhrling, 2012).

In spite of the reported powerlessness and uncertainty attached to the experience of pain, it has also been reported in several studies that women who suffer from chronic pain are eventually able to adjust to their new bodies and their new lives. This implies having to stop fighting against their bodies and their pain and incorporating changes in their attitude and lifestyle so they can balance life's demands with their time and energy. Evidently, this is not a simple and easy process since there is an important element of loss, as demonstrated in Shaefer (2017), whose findings revealed that making changes can have an impact on a different aspect of the women's life, including their income and their financial situation.

Adjustment to a life with chronic pain, can, as evidenced in Gutke et al. (2018), be a process of acceptance and adaptation, whereby women's attitudes are less focused on fighting the pain. However, the authors state that, for other women, adjustment can remain an ongoing struggle against the pain. Factors such as an accurate diagnosis and treatment, as well as support and understanding from healthcare practitioners, were found to be pivotal in the process of acceptance, as described by McCann (2015).

Theme 3 – Identity and social roles

Previous research has indicated that chronic pain has a significant impact on women's social roles and identities. For example, in Söderberg et al. (1999) women described how the pain made a significant impact on their role within their families, assuming a more passive role. Their role as mothers and wives was disrupted when having to relinquish the care of their children to their husbands or other members of the family (Engeset et al., 2014) or to ask their partners to take care of domestic tasks that they used to carry out before the onset of illness, this being a difficult change to adapt to for some families (Sturge-Jacobs, 2002).

The literature also showed that women described feelings of guilt when they realised the impact of their illness on their family members, feeling responsible for being a source of their burden (Schneider & Fletcher, 2008; Råheim & Håland, 2006; Clark, 2012; Shallcross et al., 2018; Wuytack & Miller, 2011). They also expressed feelings of guilt and felt responsible for contributing to their children's stress and being unable to attend family gatherings or important events in their children's life (Palacios-Ceña et al., 2017).

In a recent study conducted by Arman et al. (2020) the authors found that women, in the role of caregivers, tend to look after other people's needs before their own, which has a negative impact on their health. As a result of the demands that were felt as internalised, but also what society expected from them, women were unable to find time and space for recovery. These findings also resonate with Ramsey (2012), who evidences that women feel they need to push through pain in order to meet the expectations held by others and themselves and to compensate for the feelings of guilt for not fulfilling their role of significant other. This last point is also discussed in other studies, which demonstrate that, in many cases, women decided to conceal their symptoms or diagnosis from friends and colleagues or kept their illness to themselves in the presence of family in order to avoid putting an extra burden on them (Shaefer, 2017; Sturge-Jacobs, 2002).

As well as their caregiver role being compromised, the women experienced difficulties when it came to their work or professional identities, which were affected by having to take sick leave, being unable to accomplish their professional goals or their performance being compromised because of their physical limitations (Juuso et al., 2016). By losing their work role, women also reported that it took them a long time to restore their identity in life (Wuytack & Miller, 2011).

In addition, several studies show that physical problems such as pain and fatigue have a great impact on other aspects of women's identities since they are no longer able to engage with previous hobbies, leisure activities or social activities (Engset et al., 2014; Clark, 2012; Shallcross et al., 2018; Shaefer, 2017; Söderberg et al., 1999). Clark (2012) observes how, because of the ongoing levels of pain and fatigue, women had to constantly cancel plans, removing themselves from social circles, losing friends and feeling extremely lonely. In addition, the disbelief and lack of understanding that women experience results in avoidance of social events and interactions with others, a withdrawal from the world, which leads to significant feelings of isolation (Juuso et al., 2014; McCann, 2015; Sturge-Jacobs, 2002).

Some authors have highlighted the relationship between the loss of specific roles and identity and the loss of meaning. In their study Gutke et al. (2018) found that women who suffer from chronic pelvic girdle pain find themselves unable to perform meaningful daily activities, resulting in a loss of self-respect and meaning. Similarly, Juuso et al. (2016) found that, for women with fibromyalgia, their ability to work has been greatly affected by the illness; therefore, their identities are also impacted. Since we tend to place value and meaning on work, the authors suggest that it is important to help women with fibromyalgia to find new meaningful activities when work is no longer possible.

Reflections on the literature review

In the review a phenomenological enquiry was mostly used to explore the lived experience of pain across conditions and the meanings assigned to this. Together, these studies provide important insights into the lived experience of pain.

Interestingly, and despite being a key notion in phenomenology, the concept of intersubjectivity is only mentioned once in Råheim and Håland's (2006) study of fibromyalgia. The authors use the existential dimension of lived relations in order to point to some of the ways in which chronic illness affects relationships with others, thus referring to the intersubjective nature of the lifeworld.

Furthermore, the concept of the lifeworld was mentioned in several studies, mostly in relation to the aims and rationale for choosing a phenomenological method. However, it was observed that the concept of the lifeworld – central to the phenomenological tradition – was barely used as a tool to articulate and understand the findings. Only two studies, again Råheim and Håland (2006) and Ramsey (2012), anchored their descriptions within the lived experience. It is possible that this was achieved through a hermeneutic enquiry inspired by van Manen's (1997) approach, using the four lifeworld existentials (temporality, spatiality, corporeality and relationality). This does not mean that the named dimensions of the lifeworld are not covered in the rest of the studies, but, although embedded, they are not necessarily addressed from a phenomenological perspective. In the case of intersubjectivity, there are nods to the concept, which are associated with the relational and social world and how these are affected by the experience of pain. The latter is observed in the studies of Juuso et al. (2014), McCann (2015) and Sturge-Jacobs (2002), who refer to the withdrawal and isolation resulting from chronic pain.

According to Stanier and Miglio (2021), many authors who use phenomenological approaches to explore the experience of pain tend to provide a description of general structures of pain, as opposed to providing a more phenomenological articulation of how pain comes into experience in the lived world and by whom it is borne. This is in line with Lima et al. (2014), who state that, although phenomenology as a research methodology is rather present and common in the field of health, it does not stand out as a means of theoretical articulation and new ways of understanding the human experience. Dahlberg and Dahlberg (2020) state that the use of phenomenology as a research practice should not be separated from the original philosophy, since “it is only the ontological and epistemological foundation found in phenomenology and hermeneutics that can render our research scientific in the true sense” (p. 463).

It is possible to argue that the experience of pain continues to be understood from the lens of Cartesian dualism and the distinction between objective and subjective remains present. This is demonstrated in the literature when chronic primary pain is described as something personal, private and subjective and lacking in “objective” evidence. Furthermore, the intersubjective dimension, how pain is affected and conditioned by being-with-others, although present in the writing, is not necessarily revealed. Stanier and Miglio (2021) once more state that the concept of intersubjectivity can sometimes be bracketed or neglected by phenomenologists. Likewise, they argue for an understanding of intersubjectivity that is more encompassing, not only reduced to the experiences of other people but also to sociality, politics, intersubjective and collective norms. Intersubjectivity in the case of chronic pain should also be concerned with the social and political constructions that constitute the lived experience, taking into account the social divides across gender, race, ethnicity and class.

The review showed that five out of twenty-three studies were explicit in their use of gender as a central factor for understanding and analysis. Arman et al. (2020) draw our attention to the distinctive aspect of gendered suffering and how gender roles play an important part in the experience of illness and pain. In the same way, Werner and Malterud (2003) use a feminist framework to interpret their findings, highlighting the relationship between shame and dignity and power and disempowerment for women with chronic pain. Shallcross et al. (2018), Johnston (2013) and McCann (2015), in their studies on vulvodynia, also use gender in the context to explain biases and patriarchal attitudes in healthcare settings and as a determinant for identity. Although the remaining studies do allude to elements of gender, they do not fully explore how socially shared gender discourses may affect the experience of pain.

Without a doubt, the research papers selected for this study represent a large contribution to the study of the lived experience of pain, and the phenomenological exercise has proven to be a suitable choice to explore aspects of an experience that feel ineffable and inaccessible. Moreover, there is some evidence of the encompassing intersubjectivity that characterises the human experience. Nevertheless, as well as the subjective experience of pain, the intersubjective also requires attention and further elaboration. Intersubjectivity needs to be brought to the fore as a central aspect of the lived experience instead of being taken for granted. Therefore, my research aims to add to the current corpus of knowledge around chronic pain in women, from the lens of the lived intersubjective body.

After outlining and reviewing the relevant empirical literature, in the following chapter the aim is to present the epistemological underpinnings of this study, which have guided and influenced my chosen research method.

CHAPTER 3: METHODOLOGY

Introduction

Phenomenology as a tradition can adopt different variants; therefore, this chapter also aims to explain the different approaches, from the transcendental phenomenology of Husserl to Heidegger's (1927/2010) hermeneutic turn, which conceives of interpretive understanding as the central aspect of human existence. Following this presentation, I explain my rationale for the chosen method and how the hermeneutic-phenomenological approach chosen for this study is better suited than other methods such as narrative analysis or a relational-centred approach, which were also considered for this study. A section on the relational-centred encounter (Finlay & Evans, 2009) was also added to this section in order to highlight the fact that data emerges from the embodied and dialogical encounter with the participants.

In the second part of this chapter, covering the study design, I set out the methods and procedures that were used to collect and analyse the data, as well as the ethical framework that guided this research.

Epistemological position

Qualitative research is not a homogeneous field per se and researchers can adopt different positions regarding their assumptions about the nature of the knowledge they aim to generate through their research (Willig, 2008).

Various epistemological positions are adopted by qualitative researchers relating to their specific ontologies. The scientist or researcher who believes in a factual and external world will assume an objective, detached and value-free position. In contrast to this realist position, a relativist ontology will question the real and knowable world, emphasising the diversity of interpretations of experience (Langdridge, 2007; Willig, 2008).

According to Madill et al. (2000), one of the aims of qualitative research is to understand the linguistic meaning within textual material. This task involves a certain level of inference on the part of the researcher, which implies a turn from a positivist paradigm that aims to explain objective reality. According to Willig (2008), there are three broad epistemological models – realism, phenomenology and social constructionism – categories that respond to the realism–relativism continuum.

The core of my epistemological stance is predominantly phenomenological, which, according to Harper and Thompson (2011), can be placed along the realism–relativism continuum. A phenomenological type of knowledge aims to identify the social and psychological processes that underpin the subjective experience (a more realistic type of knowledge), as well as identifying the various social constructions and versions of reality (a more relativistic approach) (Willig & Billin, 2011).

By assuming a phenomenological epistemology, I adopt an approach whereby I am interested in the quality and texture of the experience. This means that I am assuming the existence of more than one world, where the experience of chronic primary pain can be experienced in different ways, assuming that there are as many worlds as there are individuals (Willig, 2008). Phenomenological approaches may differ depending on whether they fall into a descriptive endeavour or a more interpretative stance, whereby the researcher uses the other's account to reveal not only something about that person but also his/her relation to the world of objects. By revealing what they are in "themselves", the subject also reveals what they are in their relatedness to the world (Larkin et al., 2006).

Mascolo and Kallio (2020) argue that a phenomenological epistemology also challenges the strong distinction between the objective and the subjective, the outer and inner, the known and the knower, which are common in the Cartesian tradition. From a phenomenological standpoint, knowledge cannot be validated by comparing specific theories with objective events. Conversely, the authors go further, stating that social and psychological knowledge takes place in the inter-experiential space – the intersubjective processes that take place between people.

The latter coincides with what Madill et al. (2000) term contextual-constructionism, a position where both researcher and participant are interpreting beings, embedded in a world of networks and cultural meanings. The contextualised production of knowledge implies four dimensions, which, according to Pidgeon and Henwood (1997), are: the participant's own understandings, the researcher's interpretation, the cultural meanings that inform both participant and researcher and, finally, validation of the interpretation by the scientific community.

The goal of this research is to account for the intersubjective, contextual and relational aspects of chronic primary pain with the aim of contributing to an understanding of pain as a complex phenomenon rather than a purely private and subjective experience. This inevitably positions this research on a critical phenomenological standpoint by assuming that pain is not only determined by the sensations felt in the body but also a phenomenon shaped by popular discourses that determine how pain is experienced, received and signified.

As maintained by Sprague (2018), feminist studies have shown how traditional social sciences have tended, when it comes to gender, to either naturalise inequalities or hide them altogether. Transformation in social sciences is the result not of changing the scholars but of these scholars shifting the standpoints from where they generate their knowledge. This means, according to the author, that researchers generate their social enquiries from the standpoint of women, people of colour, the poor and other socially marginalised populations, creating the opportunity for analysis that identifies situations as unjust.

I am aware that during the different stages of this research, such as defining the research question, data collection, analysis and representation of the material, among others, I emphasised an interpretive stance that aimed to be transformative for women by exploring the dynamics of power and how these may have an impact on women's health (Creswell & Creswell, 2018). For this reason, this research aims to create an opportunity for the women of this study to have a voice, to feel they are being taken seriously, alongside their narratives and analysis of them. By becoming aware of the position, where I construct knowledge and the social relations and structures that come into play, the goal is to serve the cause of social and gender inequality and guide social change.

Phenomenology

As previously stated, I hold an epistemological position that leans towards a phenomenological stance with constructivist elements, which means that I am interested in intersubjective aspects of experience, placing the participant's and researcher's accounts within a specific social and cultural context.

The phenomenological approach has its origins in Husserl's (1913/1982) philosophy, which was interested in returning to things themselves, as they appear to us, describing phenomena as they appear to consciousness, free of all prior suppositions and assumptions. The philosopher stated that our natural attitude to the world is based on many assumptions that, although useful when it comes to being and doing, may also distort a proper understanding of things. By bracketing, we intend to suspend these assumptions and prejudices about the world and transcend its apparent qualities.

This phenomenological reduction, or "*epoché*", is connected to another of Husserl's principles, the "eidetic reduction", which is a process of imaginative variation. This means that, as researchers, we try to imagine alternative ways of observing a phenomenon, either by removing or varying certain features.

In addition to the phenomenological and eidetic reduction, Husserl aimed for a transcendental reduction that seeks to transcend the particulars of the situation and individual variation in order to describe the universal features of *"what something is like"* (Larkin et al., 2011).

As stated by Langdridge (2007), this aspect of phenomenological philosophy can have different takes on the viability of bracketing off preconceptions about an experience. Consequently, Husserl's transcendental phenomenology was later subjected to critics, which led to an existential turn, with many philosophers such as Heidegger, Sartre and Merleau-Ponty taking Husserl's ideas and developing and reworking his notions. These philosophical ideas have also influenced phenomenological psychology, where the interest in existence allowed phenomenological philosophy to place more emphasis on the experience of the person in her/his context and her/his lifeworld (Langdridge, 2008).

For Heidegger (1927/2010), the very thing that Husserl wanted to transcend and bracket off – the natural attitude – was in fact the most important focus of enquiry. This is the fore-grounding and the interpretative framework from which the world is understood, and from where we endeavour to uncover the structures of the sense-making being.

From this point of view, the phenomenon does not rely on the inner representations of an independent reality and does not constitute a descriptive exercise. This approach corresponds to a hermeneutic-phenomenology that understands consciousness as a mode of being-in-the-world. What Husserl wanted to transcend seemed inescapable for Heidegger, meaning that the situated everyday nature of the experience is also vital to understanding our being-in-the-world (Larkin et al., 2011).

Hermeneutic-phenomenology

Hermeneutic-phenomenology pays attention to the philosophies that underpin both phenomenology and hermeneutics (van Manen, 1997). The latter comes from a tradition of theologians' efforts to interpret biblical scriptures; therefore, hermeneutics was mostly interested in uncovering God's messages within the Bible. From this, it is possible to observe two things about hermeneutic enquiry. First, the text is seen as sacred and as carrying a very important meaning. Second, not only does the enquirer come to the text with a solid set of pre-understandings but so does the reader of those hermeneutic interpretations (McLeod, 2011). These presuppositions or preunderstandings do not require discipline; they are a given, embedded in the act of interpretation, situating the subjects of knowledge in history and related to the context that it is being understood (Unger, 2005).

The understanding of human experience, according to Heidegger, can be achieved by interpreting language, history and culture, with a particular emphasis on where the subject sees him/herself in the world. Hermeneutic-phenomenology, from this perspective, is interested in the multicolour aspects of the human world as we find it (van Manen, 1997).

This represents a turn from Husserlian phenomenology in the sense that the researcher does not need to shed all prior understanding or knowledge in order to grasp the essential lived experience of the subjects under study. A subject's reality is invariably influenced by the world in which he/she lives and, as Heidegger states, we are beings-in-the-world and therefore unable to abstract ourselves from the world. Following Heidegger's philosophical tradition, Gadamer (1960/2004) expands Heidegger's concept of the *hermeneutic circle,* emphasising the dynamics between the topic of study and the fore-structures of understanding that constitute our being-in-the-world. Gadamer poses that it is through conversation or *dialogue* that hermeneutic understanding takes place. It is through conversation that what was once concealed is now revealed. He writes:

> Conversation is a process of coming to an understanding. Thus it belongs to every true conversation that each person opens himself to the other, truly accepts his point of view as valid and transposes himself into the other to such an extent that he understands not the particular individual but what he says. (p. 387)

Dialogue is pivotal in the sense that it allows the hermeneutic circle to move by engagement with the other's discourse. It is by encountering another and introducing new ways of looking at the phenomenon that our presuppositions are challenged, shifted and made available for new interpretations.

The hermeneutic dialogue as a philosophical underpinning of the research method is inescapably linked with the interview process, since it represents the ongoing opening to possibility, a dialectic endeavour because, for Gadamer, it is "the art of conducting a real dialogue" (1960/2004, p. 360).

Another important element of hermeneutic philosophy is related to its posture when it comes to *interpretation.* According to Gadamer (1960/2004), interpretation is determined by prejudices – originally conceived as negative within the scientific research community – which are fundamental in the process of understanding. For the author, the subjectivity of the researcher should not be suspended (already an impossible task); on the contrary, the researcher should intentionally engage with his/her prejudices throughout the meaning-making process. The researcher seeks to understand a text that is framed by what Gadamer termed "historical consciousness", whereby the understanding of the text or event is grounded in a set of cultural constructs, which are embodied in language. There is a fusion of horizons between the world of the interpreter and that of the text. This form of tradition-informed interpretation is at the core of the hermeneutic-phenomenological approach to enquiry.

McCraffey et al. (2012) pose that Gadamer's concept of prejudice is what enables us and we simply cannot see without it; prejudice is part of the condition of understanding. What really matters, when it comes to the hermeneutic enquiry, is the careful and reflexive attitude by which we do not fall into the trap of taking our prejudices for conclusions. The hermeneutic endeavour is metaphorically represented by the authors as being "… like an archaeologist finding a pottery shard, which then takes on meaning as it is interpreted in light of its connections to its historical, social, cultural, aesthetic, and political worlds" (p. 223).

For both Heidegger and later Gadamer, language is the means by which we understand the world that we inhabit. Heidegger (1967/1998) argues that "language is the house of Being" (p. 254) and discourse is the way that the meaning of the world is revealed for *Dasein*. This conception of language is intrinsically interpretative, as well as aesthetic and self-expressive, which challenges the view of words and language as objective entities. Koch (1996) suggests that the process of writing should retain an ecological sense by making connections between the interpretative writing, data and literature. From this perspective, the task of hermeneutic writing is to use the hermeneutic circle, whereby the parts and the whole of the text and interpretations are related to one another.

As well as dialogue and interpretation, *reflexivity* is also considered an important element in Gadamer's tradition, whereby the circle of understanding is expanded to include the dynamic between the text and the fore-structures of understanding. He states that "working out this fore-projection, which is constantly revised in terms of what emerges as he penetrates into the meaning, is understanding what is there" (1960/2004: p. 269). This is the ongoing process of reflection and revision, whereby the iterative questioning shifts the researcher's assumptions and illuminates the new understandings and interpretations. McCaffrey et al. (2012) reconfigured the image of the circle into a spiral to demonstrate the ongoing movement of understanding and interpretation that can never return to its previous position.

In contrast with the traditional research frameworks, where the researcher is conceived of as a detached subject who searches for objective truth, qualitative approaches such as hermeneutic-phenomenology recognise the role of the researcher as a co-producer of psychological knowledge.

Reflexivity refers to the process whereby the researcher is conscious and reflective about the way the questions, method and position in the world (ethnicity, gender, socio-economic status, etc.) could impact the conclusions produced in the study (Langridge, 2007).

The rationale for the chosen method

Hermeneutics can be very useful for exploring complex and multi-layered meaning phenomena that can be viewed from different perspectives. It is for this reason that a hermeneutic approach to the experience of pain represents a good alternative when seeking to understand and open up the complexity of the pain experience.

In addition, Gantt (2000) argues that a hermeneutic approach is sensitive to both the historical and sociocultural situatedness of human experience, where understanding aims to provide sensible and meaningful accounts of contextualised problems. This is in contrast to a positivist paradigm, more concerned with uncovering ahistorical and atemporal structures of reality. Moreover, the author states that a hermeneutic-phenomenological approach reminds us that suffering, and its meanings, are never a private experience. Suffering has social and moral qualities involving those directly affected by it but also those called to respond and answer for it:

> Thus, the meaning of suffering is, from within a hermeneutic-phenomenological framework, never solely the property of the autonomous and freely willing individual resolutely forging meaning, but rather it is the negotiated and socially constructed product of our human (inter)relatedness and responsibility to and for one another. (p. 18)

The experience of pain is an experience of suffering, which is also situated, temporal and historical. Pain, conceived as suffering, has a social and moral element that can be addressed by a hermeneutic approach that seeks to uncover its intersubjective understandings and meanings.

My position as a researcher implies an attitude that aims to challenge the idea of pure objectivity and universal knowledge and also intends to produce knowledge that is immersed, situated and open to new interpretations. From this position, I was always determined to assume a more interpretive phenomenological stance throughout the research.

Interpretative phenomenological frameworks such as interpretative phenomenological analysis

(IPA) have been widely used in psychology and similar disciplines. It has made an important contribution to the experiences of illness, including many studies on the experience of pain (Smith & Osborn, 2015).

The popularity of these interpretative approaches within the field of health psychology stems from their contribution to a biopsychosocial and inductive approach steering away from hypothesis testing and mainstream assumptions. These characteristics are considered of great value in the national service framework, where nowadays efforts are being made to listen to patients, allowing them to express their views and opinions (Smith & Osborn, 2015). Given its popularity within the field of psychology, and its structured and methodical approach, appealing to a novice qualitative researcher, IPA presented itself as a suitable option. Nevertheless, as Lima et al. (2014) would argue, although phenomenology is quite commonly used as a research methodology in the field of psychology, it is seldom used as a theoretical articulation. van Manen (2018) states that IPA's emphasis on analysis, which at times can be seen as mechanistic and lax, overlooks the intuitive grasp of meaning involved in phenomenological enquiry. Intuition is understood as "'seeing' the essential meaning of an existential situation, phenomenon, or event" (p. 1963).

As previously stated, this research aims to address the problem of pain from a phenomenological standpoint; phenomenology, in this case, is reduced not to a methodology but to a philosophical underpinning to articulate new meanings. From this perspective, a hermeneutic approach offers an interpretation whereby the analysis of the text aims to be understood reflectively, within the situated lived experience and not from a purely cognitive effort.

Since this research is interested in the lived and situated experience of women with chronic primary pain, I opted for the hermeneutic-phenomenological method described by van Manen (1997). The purpose is to grasp the meanings, the essence of the experience, and what is revealed to us of its particular significance that was previously unseen. Moreover, the hermeneutical approach has the benefit of the intersubjective structures of meaning, as proposed by Taylor (1985). The author also states that meanings are not the property of one individual or another but rather the result of social interaction among individuals within a specific context. As well as being intersubjective, the meaning is also historical, situational and dialogical, and for this reason it requires understanding and interpretation.

According to van Manen and Adams (2010), phenomenological research is interested in the lifeworld and our immediate and pre-reflective experience of it, rather than being a conceptualisation or categorisation exercise. Lived or experiential meaning are described and interpreted as they appear, being shaped by language, consciousness and personal, cultural and social preunderstandings. It is expected that phenomenological research will have an effect that eventually allows us to grasp the human phenomenon, thus enriching our understanding of the experience of pain. This is done by creating a text that speaks to our cognitive and noncognitive sensibilities, allowing for an understanding that is "existential, emotive, enactive, embodied, situational, and nontheoretic" (449).

For Grenz (1996), the researcher creates a relationship with the text, "hermeneutic conversations", which reveals a new understanding of the phenomena. This relationship between the interpreter and what is being interpreted can be considered a methodological step that originates in Heidegger's philosophy and involves understanding the being of something, such as the text, through the iterative movement between the whole and the parts. This means that initial assumptions can later be challenged or revealed as partial or wrong, creating new understanding and interpretations (Finlay, 2011).

For van Manen (1997), themes, or structures of meaning, are not objects or generalisations; phenomenological themes are "more like knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes" (p. 90). This makes sense when it comes to the experience of pain, understood as a shared phenomenon and the result of interrelatedness that takes place in a specific context. For Heidegger (1927/2010), exploring the being-in-the-world, or the experience of pain in this case, needs to be done in the context of "being-with-others", the everyday existence through the interaction with others. Even though hermeneutic-phenomenology does not have a particular method, and it may even be considered proscribed by this approach (Finlay, 2011), there is still a body of knowledge that can work as a source and methodological ground. According to van Manen, this ground can be organised into six methodological themes or research activities:

I. Turning to the nature of the lived experience: Phenomenological research is a project of someone, and the interest and commitment in the particular phenomenon are embodied in the individual, who belongs to a particular context. In this sense, the phenomenological description is always one interpretation of the human experience, meaning that there will always be the possibility of another complementary description.

II. Investigating experience as we live it: This follows Merleau-Ponty's (1945/2002) idea of re-learning how to look at the phenomena by reawakening the basic experience of the world. In this sense, we turn to the phenomenon as we live it in that precise moment instead of conceptualising it.

III. Hermeneutic-phenomenological reflection: This means that the researcher can thoughtfully reflect on the essential themes and meanings of that particular experience. This process involves clarifying and making explicit the structure of those particular meanings that are communicated textually in organised narrative or prose.

IV. Describing the phenomenon through the art of writing and rewriting: The object of phenomenological research is to create a phenomenological text, bringing something to speech; to bring some aspect of the lived experience into something intelligible. This requires the ability to be sensitive to the undertones of language and allow things to speak for themselves.

V. Maintaining a strong and oriented psychological relation to the phenomenon: Phenomenological research is characterised by the demanding task of remaining strongly oriented towards the fundamental question or notion of the research. The validity of the study is therefore enhanced by avoiding narcissistic reflections or falling back into abstract theories that are cut off from the ordinary lifeworld.

VI. Balancing the research context by considering parts and whole: The argumentative text aims for a certain effect that, at times, might get lost in the parts. This requires the researcher to constantly evaluate the design of the study or text and be able to understand the role of the parts in the total structure of the research. This reminds us of the *hermeneutic circle*, the process of understanding the being of something by moving iteratively between the whole and the parts. The interpreter and what is being interpreted move between previous and new assumptions that are constantly challenged and understood in a different light (Finlay, 2011).

Consideration of alternative research methods

When thinking about pain, I was also interested in the narratives that we use to make sense of our experiences that bring order to the disorder (Murray, 2000), which made me consider narrative analysis as a methodological framework. I was also interested in the fact that narrative research tells the story of individuals within their personal, social and historical context (Creswell & Creswell, 2018), which spoke of the situatedness of experience.

For narrative researchers, our lives are storied, which means that we are born in a narrative world, we live our life and describe it through a particular narrative. The stories we tell give coherence and order to events in our life, giving continuity and defining our sense of self. The different events, either significant or disruptive, that an individual experiences are placed in a "life story", where the subject is, at the same time, the main character and the narrator. Furthermore, the way that this particular story develops is rooted in our relationships and shared community (Breakwell, Smith & Wright, 2012).

I was particularly drawn to Frank's (1995) model, a Canadian sociologist, who was diagnosed with cancer and who developed an interest in the nature of the stories that people tell about their illnesses and what gives them shape.

The author considers that during (or after) sickness it is not just our body that is threatened but our own identity. Telling a story also has another function, a self-care function that allows the ill individual to take control of the illness and bring order to a chaotic world (Murray, 2000). Frank's approach to narrative analysis is interested in the way that storytellers "sustain a relational self that is threatened by some crisis" (2000, p. 355); stories are told to/with other listeners who are part of that storytelling and therefore the storytelling is the relationship. This last point made me consider this approach as a methodological alternative since it incorporates the relational elements in the analysis, addressing the intersubjective aspects of experience.

Frank (1995) distinguishes between three kinds of illness narrative: the restitution narrative, the chaos narrative and the quest narrative. The chaos narrative is characterised by a present that lacks a memorable past and has no future worth anticipating. Control has been lost and life does not seem to get any better. The chaos narrative can be also reflected in the way the story is told; stories are difficult to hear, lack order and can often be distressing. The restitution narrative, on the contrary, suggests an end to that chaos by having as a goal the recovery from illness, being able to see a preferred end to the story. Finally, the quest narrative is when the illness experience transforms the individual by being able to rise above the challenges of the illness and overcome the suffering.

Although I was initially drawn to Frank's approach to narrative analysis, I was missing the engagement with the phenomenological and hermeneutical elements of the analysis, which I consider to be a more novel contribution to the experience of chronic pain. This last aspect led me to consider Langridge's (2007) critical narrative analysis (CNA) because of its reliance on a phenomenologically informed narrative analysis. This type of analysis bridges a gap between phenomenology and discursive psychology through engagement with elements of social theory such as Ricoeur's (1970) *hermeneutic of suspicion*. It is through the latter that new interpretations can be generated by digging under the surface, thus providing an opportunity to cast doubt "over the initial empathetic account of meaning" (Langridge, 2007, p. 44).

This type of narrative approach has the benefit of acknowledging the impact of situatedness, taking into account the impact of social discourses on the narratives of pain in women, which made CNA an interesting choice for this study. However, after careful consideration, I considered that the intersubjective experience of pain was a more encompassing concept that required further unravelling in order to engage with other layers of analysis. I was concerned that the balance between phenomenology and hermeneutics of suspicion would be difficult to obtain. This reflection consolidated my decision for an analysis that, as well as being hermeneutic, was also phenomenological. Furthermore, I was aware that CNA is highly ideographic and better suited to single case studies. Although Langridge (2007) does not reduce this as a single possibility, he stresses that, even when using a small number of participants, this type of analysis is laborious and intensive. Considering my novel status as a researcher and the time constraints of this research, this analysis did not seem particularly suitable.

Bearing in mind that this study places special emphasis on intersubjectivity, due consideration was given to Finlay and Evans' (2009) relational-centred research approach, which incorporates different theoretical concepts from philosophy and psychology, having an existential–phenomenological philosophy at its core. I was drawn to this approach since it understands consciousness as embodied, intersubjective intentionality. In this regard, research does not assume that the participants will be talking to a passive and distanced researcher. On the contrary, we are talking about a constantly evolving, dynamic and co-created relational process that it is more about *being with* than *doing to*. I also considered that this approach would be suitable for a psychotherapist, whereby my professional competencies and emotional literacy could be seen as a useful tool for research.

Although I felt very inspired by Finlay and Evans' (2009) relational-centred research approach because of the particular emphasis on embodied intersubjectivity, I reflected on the fact that being new to research might present as an obstacle when using an approach that does not provide a methodological ground or specific linear steps.

According to Finlay (2011), the relational-centred approach can be specifically applied to phenomenological research, when the focus is placed on the relational dynamics between researcher and co-researcher, which are then analysed and explored reflexively. At the same time, this approach can also be seen as a general orientation for any qualitative project that advocates for the need to pay attention to the embodied intersubjective relationship between the researcher and the researched. Although I decided not to use this approach as a methodological articulation, I opted to hold it as an orientation that paid attention to the research relationship or relational-centred encounter, which will be described in the following section.

A relational-centred encounter

As a phenomenological researcher researching the lived intersubjective experience, I position myself as recognising that I am a part of the world being studied and that data comes from the embodied relationship between researcher and participant (Finlay and Evans, 2009).

With this in mind, I adopted a relational-centred attitude at the time of encountering the participants and co-creating the data. I consider this attitude to be a pivotal aspect of research when it comes to exploring intersubjectivity and the relational world. In addition, the use of the psychotherapy skills that I have acquired in recent years enabled me to explore the embodied intersubjective space between researcher and co-researcher, allowing rich data and experience to emerge.

The researcher's attitude that I adopted during the encounter with the participants was characterised by the following features of relational research:

I. Presence

The researcher's presence is crucial for the research relationship. This required the researcher to be emotionally and bodily present, being in contact with my bodily emotions, thoughts and feelings while staying empathetically engaged with the participants. At the same time, I endeavoured to remain open, putting aside previous understandings of the phenomena and remaining curious and open to its different possibilities. I aimed to be openly present to whatever emerged, prepared to cope with the uncertainty that mutual vulnerability and difference may have implied. It is precisely this presence that allowed the possibility of the "between" and the simultaneous dynamic of being together and apart.

The authors emphasise that presence is not a technique or something that needs to be displayed as part of a role, or about "doing", but rather a way of being that is first and foremost an authentic way of "being-with".

II. Inclusion

From a relational perspective, it is expected that both researcher and participant can recognise the other as a separate individual in his/her own right but be able – at the same time – to understand the uniqueness and wholeness of the other. This means that my goal was to be able to stay in my world of experience, empathise with the participant and observe this mutual dynamic from a meta-perspective.

The term inclusion was used by Martin Buber (1947/2002) when describing the capacity of "imagining the real", a form of knowledge that does not reduce the particularity of the other under a universal category but assumes it to be unique for a specific person. The philosopher also makes a distinction between empathy and inclusion whereby, in the latter, the person lives through the shared experience from the standpoint of the other but does not give up his/her point of view (as would happen with empathy).

As a relational researcher, I let myself be affected by the experience of the participants, the grief, anger and frustration, allowing emotional responses to be elicited by the experience of the other but at the same time remaining in my own experience. This assumes that in the relationship between researcher and co-researcher there was a degree of mutuality and influence of self on other and other on self. This can only take place when there is an element of presence that will enable a sense of mutual influence and engagement.

III. Intersubjectivity

A central theme of this research is the concept of intersubjectivity, and during the relational encounter special attention was placed on the relational ground between researcher and co-researcher.

Empathy and understanding are only possible through our corporeal commonality and the capacity to create intersubjectivity. Our bodies are in a primordial relationship with others and the world. As stated by Todres (2007), the body is not merely fleshly perceptual. The body is fundamentally intentional relational and full of implicit meanings and co-arises within the situation.

When conducting relational research, both researcher and co-researcher bring the multifaceted, contextualised and relativised self, meeting each other in all their complexity. The life experience of both will interact with and impact each other.

In this particular sense, it was important to acknowledge as a researcher that I am also a being of family, social and cultural contexts. For Heidegger (1927/2010), culture and collective identities permeate and give life to our lifeworld in delicately pervasive and indeterminate ways, which can be both seen and not seen (Finlay, 2009).

Finlay and Evans (2009) use Merleau-Ponty's (1964/1968) concepts of reciprocal insertion and intertwining to describe the intersubjective context and the complexity that arises between researcher and participant. This complexity is characterised by the intertwining of mutual multiple levels of experience that are inhabited by different interacting subjectivities, giving way to what De Young (2003) terms *"thickly populated"* encounters.

IV. Reflexivity

Both participant and researcher bring their personal histories that have shaped their way of being-in-the-world and assign meaning to their experiences. Along with their stories, they also bring their context, age, gender, ethnicity and personality, which will evoke different meanings for both parties, therefore influencing the relational encounter.

The concept of reflexivity is important for relational-centred research and also for hermeneutic research, which involved an active evaluation of my experiences, understandings, values, motivations, culture, and so on.

To fulfil what has previously been stated, as a researcher I aimed to examine reflexively how aspects of my conscious and unconscious self could have an impact throughout the research process, making explicit the intersubjective elements that influenced the data collection and analysis. Reflexivity, therefore, was an effort to aim for transparency and trustworthiness throughout the research process. In addition, I was thoughtfully and critically self-aware of broader dynamics and processes of the relational field, such as power dynamics, that could be at play. As Finlay and Evans (2009) state: "The issue at stake is the need to appreciate how the researcher and the research relationship may impact both the research process and findings" (p. 121). The researcher's subjectivity and intersubjectivity need to be foregrounded to begin the process of separating what belongs to the researcher rather than the researched. This exercise of reflexivity prevented me from imposing meanings and understandings on the research process.

In order to practise reflexivity throughout this research, I considered the exercise of reflective writing to be very important, and for this reason I used a research diary where I wrote different thoughts and feelings that arose at different stages of the study, ongoing reflections on my motivations for the chosen topic, quotes, poems, embodied feelings during and after interviews, and further reflections while analysing the findings. I tried to remain mindful of my own prejudices and opinions throughout the process to prevent imposing my worldview on the research.

Study design

This was a small qualitative study using semi-structured interviews. Rich and in-depth accounts were generated to answer the research question. The data was later analysed using a hermeneutic-phenomenological approach, which allowed the different structures of meaning to emerge. The research was conducted following the British Psychological Society's (BPS) Code of Human Research Ethics guidelines.

Sampling and participant inclusion criteria

I used purposive sampling since I considered it to be the best strategy to identify and select information-rich cases for the best use of limited resources. This meant that I was able to identify and select individuals that were especially knowledgeable about the experience of chronic primary pain (Palinkas et al., 2015).

Because interpretative phenomenology results in large sets of data given the rich and in-depth accounts, sample sizes need to be kept relatively small (Mason, 2002). For this reason, I set out to recruit between six and eight participants.

For the purpose of this study, I aimed to recruit women who fulfilled the ICD-11 criteria for the chronic primary pain classification (Nicholas et al., 2019):

Chronic primary pain is defined as pain in one or more anatomical regions that:

(1) persists or recurs for longer than three months;

(2) is associated with significant emotional distress (e.g. anxiety, anger, frustration or depressed mood) and/or significant functional disability (interference in activities of daily life and participation in social roles); and

(3) where the symptoms are not better accounted for by another diagnosis.

The inclusion criteria at the time of recruitment were as follows:

- Pain is characterised by significant emotional distress (anxiety, anger/frustration or depressed mood);
- Pain is characterised by functional disability (interference in daily life activities and reduced participation in social roles);
- Pain experienced for over a year;
- Living in Greater London;
- Able to communicate in English; and
- Able to attend the interview meeting in a London location.

Even though some exclusion criteria were considered for the purpose of this study, such as the mental health of the participant and having a terminal illness, I decided not to include them for further consideration. This decision was based on the acknowledgement and recognition that people in such circumstances should not be assumed to be unable, or whose contribution is less valid, because of a particular diagnosis.

The rationale for inclusion criteria

I chose the category of chronic primary pain, as defined by ICD-11, because it is a category that was recently created that addresses the complex interplay of biological, psychosocial and social factors, aiming to avoid the outdated dichotomy of “physical” versus “psychological” (Nicholas et al., 2019). In addition, this category of pain is likely to resist diagnosis and treatment and is associated with significant emotional distress and functional disability. Therefore, I am hopeful that the descriptions obtained from the participants will be relevant to the field of counselling psychology.

I decided to restrict the inclusion criteria to women only, since this is what the research question addressed. Participants also needed to be over the age of 20 and under the age of 75 in order to exclude minors and the very elderly on the grounds of their supposed vulnerability.

Recruitment process

Recruitment was carried out through online support groups on Facebook pages, community apps such as Nextdoor and also through recruitment emails, posters and flyers (Appendix 2) distributed among acquaintances who were able to identify potential participants.

Eight participants got in touch via email, expressing their interest in participating in this research after seeing the flyer posted online. Table 1 indicates where the participants were recruited from.

Table 1. Participants Recruitment Table

NAME	RECRUITMENT SOURCE
Ruth	Nextdoor App
Elena	Referred by a friend who saw the ad on Nextdoor App
Maryam	Facebook - Fibromyalgia support group
Vanessa	Facebook - Fibromyalgia support group
Nataly	Facebook - Fibromyalgia support group
Dorothy	Health Unlocked
Jane	Facebook - Migraine support group
Toni	Fibromyalgia support group

An initial screening was conducted by telephone in a careful, respectful and empathetic manner. During this screening interview, we discussed the nature of the interview, the depth of the questions and the possibility of being upset when talking about their difficult experiences of pain. I also emailed them the Participant Information Sheet (Appendix 3). Once they had agreed to do the interview, we agreed upon a date, time and location that was convenient for them.

The recruitment process involved a strategy that aimed to gain a sample that was representative but also varied. The first eight participants who decided to take part in this study represented variety in the sense that despite their commonalities, their experiences were diverse and unique. Six of the participants had a diagnosis of fibromyalgia which may indicate a lack of diversity in the sample, however, it is possible to say that in most cases, this diagnosis was also accompanied by other chronic pain conditions such as IBS, migraine, carpal tunnel syndrome, abdominal pain, which provided rich and varied data. More information regarding the medical history of the participants is detailed in Table 2.

Participants' ages ranged from 21 to 60 years old which also provided varied demographic data. At the time of the interview, each participant regardless of their diagnoses offered a similar yet different account of their lived experience of chronic pain. Although chronic pain was the common factor, I thought that each of them had something new to contribute to the study; their narratives, their relationship with others and the world and the unfolding meanings assigned to their experience of pain.

Table 2. Participants' Chronic Pain conditions

NAME	AGE	CONDITION	MEDICAL HISTORY
Ruth	55	Back pain – osteoarthritis	Had an accident in early 20s, has been in moderate pain since then but pain became worse since 2011. Pain in different regions of the body mostly legs, hips, neck. Recently told it was degeneration of the bones, osteorarthtis pain
Elena	53	Fibromyalgia	Suffered migraines from a young age. Had a bicycle accident in 2010 and has been in pain since then. Diagnosed with fibromyalgia in 2017
Maryam	60	Fibromyalgia	Carpal tunnel when she was in her 40's. The pain was left untreated and developed into widespread pain since then. Was diagnosed with fibromyalgia in 2019
Vanessa	21	Fibromyalgia	Diagnosed with fibromyalgia in 2019 after sudden presentation of symptoms.
Nataly	38	Fibromyalgia	Muscular pain, menstrual pain and headaches since age 17. In her early 30's began to suffer from severe abdominal pain and lower back pain and was then diagnosed with abdominal thrombosis. This was followed by a fibromyalgia diagnosis
Dorothy	27	IBS – hip pain	Severe period pain when at university followed by IBS characterised by severe abdominal pain. Pain extended to hips, experiencing femoral nerve pain. She currently lives with chronic abdominal and hip pain.
Jane	28	Migraine – fibromyalgia	Moderate headaches from the age of 10 which got worse and expanded to neck and temple when she was older. Chronic neck pain and migraines. In 2018 she was diagnosed with fibromyalgia after experiencing ongoing widespread pain.
Toni	38	Fibromyalgia	Began with joint pain in 2010, followed by chronic migraines and IBS. Diagnosed with fibromyalgia in 2016.

Data collection

According to van Deurzen (2014), when we carry out phenomenological research, we are in a relationship with our participants and our task is to enable them to participate in their own phenomenological investigation. In this sense, the dialogue was a central aspect of this phenomenological research. I therefore ensured that the interviews for my research were not conducted through questionnaires or structured interviews, although I did have a few prompt questions to help the participants describe their experience (Appendix 4).

Furthermore, I considered hermeneutic interviewing (van Manen, 1997) to be the best choice of data collection, since it allowed the question about the phenomenon of pain to remain open, facilitating a collaborative hermeneutic conversation. The latter encouraged the participants to reflect on their experience of pain, becoming co-investigators of the study.

By holding a relational-centred approach (Finlay & Evans, 2009), I was aware that the interview had to be approached as an encounter, a dialogical process where both researcher and participant contributed. For this reason, I paid attention to our embodied presence, I maintained an empathetic attitude throughout the interview and I became open to different possibilities of meaning that could have emerged in the intersubjective encounter.

Six of the interviews were conducted face to face. One participant was not able to travel to North London to meet in the consulting room and she did not feel comfortable having the interview at home, therefore, we agreed to meet in a café nearby where she lives so she did not have to commute far. Before confirming this, I made sure that she was ok with this.

It was important to consider that noise would not affect the recording and that we would be able to hear each other adequately. Similarly, it was important to address privacy and make sure that the participant felt comfortable. At the café, I chose a spot that provided enough privacy for her to talk and for us to hear each other properly and checked with her again whether she was comfortable there before going ahead with the interview, which she did.

The Covid-19 pandemic meant that two of the interviews had to be conducted online via Zoom rather than face-to-face. Although this was not originally planned, and I was concerned that this may have had an impact on the quality of the encounter, the online interviews provided safety and comfort for both the participants and the researcher. This allowed an encounter that was equally open and present as it was in the case of the face-to-face interviews.

At the onset of the interview, the participants signed the Consent Form (Appendix 5) and, once finalised, I gave them the Debriefing Sheet (Appendix 6), which covers general aspects of the research, as well as a list of organisations and support groups should they wish to seek further support. The interviews lasted between an hour and ninety minutes and were recorded with a digital voice recorder.

I remained mindful of the fact that we were discussing personal and difficult themes; therefore, I ensured that, towards the end of the session, I had a quick check-in with the women to make sure they were fine, as well as expressing my gratitude for their participation in this research. All the participants were offered to review the transcript of their interview and three of them asked to do so. A copy was sent via email for them to review. Two of them confirmed they were ok with the transcript and one of them expressed the desire to make some changes but ultimately did not go ahead with them. This was an opportunity for them to make amendments if needed and also to reflect on their experience such as it was the case for one of them who noticed that she was “jumping from one subject to another”. She was reassured that this was not a problem and that her contribution was greatly appreciated.

Analysis of the data

In qualitative research the data gathered from the interviews can be analysed in many ways and this varies according to the researcher’s choice of methodology, the type of data collected and his or her own predilections (Magill, 2009).

More than generalising theories about human experience and the real world, qualitative research aims to pay attention to the “shared world” that is created in the interpersonal experience, the shared meaning that subjects attribute to their personal experiences. The descriptions obtained from the participants were not transformed into statistical data; rather, I intended to create comparisons between these descriptions to find common meanings (van Rysewyk, 2017). I aimed to gain a deep insight into the participants’ experience of pain within their specific context and their uniqueness.

For van Manen (1997), the meanings of a phenomenon have a multi-layered and multi-dimensional nature and the interpretation of this meaning involves a process that requires insightful invention (my own interpretation), discovery (the product of my dialogue with the text) and disclosure of meaning (the interpretive product "given" to me by the text). The structure of the meaning of the text is given by themes, which are meaning units, the experiential structures of the phenomenon.

The disclosure of meaning from a hermeneutic perspective is about revealing those marginal elements within the experience that may be taken for granted (Alsaigh & Coyne, 2021), such as the case of intersubjectivity.

The phenomenological exercise cannot be reduced to acts of description, explanation and questioning of the researched lifeworld. Phenomenological writing needs to evoke a type of understanding of a primal experience that lies beyond the propositional discourse. Following this, “the ambition of phenomenological writing is contact: to touch the lived meaning of a phenomenon to be able to be touched by it” (van Manen, 2014, p. 282).

In order to uncover or isolate the themes and subthemes, the verbatim transcripts were analysed through several readings and an ongoing reflective process following van Manen’s three approaches. First, I used the holistic approach, reading each interview transcript as a whole, with the intention of elucidating phrases that could capture the fundamental meaning of the text in its entirety. Trying to use their own words, in an attempt to inhabit their world of experience, I tried to capture the main theme that would encapsulate the essence of each narrative.

Following this, I used the selective approach, reading each of the transcripts several times and highlighting phrases or statements that seemed revealing about the phenomenon of chronic pain and then grouping them into more specific themes. Each of the themes had a list of quotes that supported the analysis.

Lastly, I used the line-by-line approach with each transcript, intending to reveal the experience described in that particular sentence with the purpose of providing specific meaning and relevance. An example of this can be found on Appendix 7 where I demonstrate this procedure with the pilot interview transcript.

This interpretative exercise allowed me to discover new meanings that had not been discovered in the first reading. Towards the end of this process, I had a list of interpretative statements that I then grouped into specific themes.

Throughout these three stages of analysis, I used triangulation by involving the input from my research supervisors in order to enhance the rigour and validity of my findings.

This type of triangulation, called Investigator Triangulation, allowed for both confirmation of my findings and also different perspectives, which added breadth to the research (Carter et al., 2014).

In addition to this, I also kept a journal with my annotations and reflections to avoid blending what belongs to me and what belongs to the text. I kept note of my feelings and impressions during the interview, ideas that came to mind during the transcription process and any other relevant thoughts or feelings that constituted my own “horizon”.

Following the detailed process of descriptive analysis, which, according to van Manen (1997), is both an interpretative and hermeneutic effort, I gathered all the themes identified during the first, second and third reading of each transcript and transferred them all to the main list. After reading the list several times, I colour-coded each theme to regroup them under a more specific category. Following this process, nineteen categories were created and then distilled into three overarching themes and subthemes (Appendix 8). This process was rigorously and reflectively made by working and reworking subthemes, themes and general themes several times, as well as re-reading the transcripts, until I finally felt that the overarching meanings were representative of participants' experiences.

Ethical considerations

Qualitative studies rely on methods that result in the production of text rather than numerical data. For this reason, the qualitative researcher is considered to be the research instrument (Sanjari et al., 2014). The relationship established between researcher and participants in qualitative research can give rise to different ethical concerns, which means having to face dilemmas such as the establishment of open and honest interactions, respect for privacy and avoiding misrepresentations (Waruszynski, 2002).

This study counts with the approval from the Ethic Committee at Middlesex University which was obtained before the recruitment of the participants.

I am also committed to the British Psychological Society (BPS) human research ethics principles, which are as follows (British Psychological Society, 2021):

1. Respecting the autonomy and dignity of the participants: The researcher has the responsibility to follow procedures for confidentiality, anonymity, valid consent, fair treatment and due process. To guarantee this, the participants were given a participant information sheet with detailed information about the study, as well as a consent form (see Appendices 2 and 4). As a means to ensure confidentiality, the information provided by the participants was anonymised, with any names or identifying information changed or removed to guarantee their privacy. Personal identifying

information was stored securely in locked filing cabinets and encrypted on the researcher's personal computer.

2. Aim for scientific integrity: This study was designed and conducted with the aim of ensuring quality, integrity and contributing to the field. Ensuring quality meant that the design of this study took into consideration the potential risks or harm involved, following specific protocols to avoid the latter. In addition, the aims of this study were expected to be as transparent as possible so it has always been clear what it intends to achieve.
3. Social responsibility: The purpose of this study is to generate psychological knowledge that supports a beneficial outcome and has the potential to contribute to the "common good".
4. Maximising benefit and minimising harm: As a researcher, careful attention was placed throughout the different research stages on minimising the potential risks. In addition, a risk assessment was conducted regarding the practicalities of conducting the fieldwork. Because of their pain condition, it was paramount to offer participants the possibility to conduct the interviews at their homes if needed to avoid any worsening of the symptoms and making them feel comfortable. As a researcher, I also needed to remain sensitive to the potential emotional impact of their involvement in this research, which was indicated in the Participant Information sheet. I also made sure that they were feeling comfortable and safe during the interview, and they were reminded that they could stop at any time in the case of feeling overwhelmed or distressed. Once the interview concluded, we had a short debrief where I asked the participants how they felt, as well as reassuring them about the value of their contribution. A Debriefing Sheet (Appendix 6) was given at the end with sources of help and advice for people with chronic pain in case they were interested.

My ethical position is also in agreement with Aluwihare-Samaranayake (2012), who states that, when conducting research, an intersubjective lens is necessary, one that holds the principles of beneficence, non-maleficence, justice and respect. Research should therefore be enabling for the participant and should also facilitate the humane transformation to achieve empowerment.

Rigour, relevance, resonance and reflexivity

Finlay and Evans (2009) state that good qualitative research should be trustworthy and transparent throughout its process, also having an impactful outcome. Finlay (2011) argues that "the value of qualitative research needs to be demonstrated, argued for and justified" (p. 262). Furthermore, the evaluation criteria to which qualitative studies are submitted differ greatly from quantitative research, which aims for reliable measures to be replicated. For this purpose, qualitative studies require evaluation criteria that respond to their specific values and goals. They also need to acknowledge that limiting the criteria for truth means that research restricts further possibilities for knowledge also assuming a position of privilege for those whose cultural truth is considered to be the "correct" one (Yardley, 2000).

With the purpose of evaluating this study, I have been guided by Finlay and Evan's (2009) 4Rs, or four principles of evaluation criteria: rigour, relevance, resonance and reflexivity.

- Rigour: This principle is concerned with whether the research process has been managed in a competent and systematic manner, being able to demonstrate critical thinking. The researcher needs to show coherence, as well as plausible interpretations that can be found in the evidence. In order to demonstrate this, I have offered in the Methodology chapter a detailed description of the methodological decisions taken in order to evidence the transparency of the process, as well as explaining the rationale behind such decisions. Similarly, quotations from the participants have been included in the analysis of the data so that evidence can be illustrated in the themes.

- Relevance: This aspect of the evaluation seeks to ensure that the research will add to the existing body of knowledge on chronic pain, helping to further understand the phenomena. Similarly, the study needs to be relevant for the specific fields involved in chronic pain research and care, as well as its possible applications in the areas of counselling psychology and psychotherapy (as will be addressed in the Discussion chapter).
- Resonance: It is expected that the findings of the study will be sufficiently evocative that they can tap into the emotional, artistic or spiritual dimensions of the reader so they can feel drawn in, eliciting an emotional response that is powerful and resonant and that, at the same time, has the capacity to challenge what has been taken for granted. This study provides an invitation to immerse oneself in the lived experience of chronic pain, from an intersubjective perspective, hoping that the reader can relate as both pain-bearer and pain witness.
- Reflexivity: As previously stated, reflexivity represents the capacity for openness and self-awareness throughout the research process, with the aim of achieving transparency and trustworthiness. I remained committed to examining reflexively how my own worldviews could be having an impact on each step of the research. I kept a diary and made notes throughout in order to separate what belonged to me and what belonged to the participants.

In the next chapter I present the analysis of the findings, with the hope that they can be a respectful representation of participants' experiences.

CHAPTER 4: ANALYSIS OF THE FINDINGS

> *Suffering unhouses and dislocates you. Suffering is the arrival of darkness from an angle you never expected. There are different kinds of darkness. There is the night when the darkness is evenly brushed. The sky is studded with the crystal light of stars and the moon casts mint light over the fields. Though you are in the darkness, your ways are guided by a gentle light. This is not the darkness of deep suffering. When real suffering comes, the light goes out completely. There is nothing but a forsaken darkness, frightening in its density.* (John O'Donohue)

Introduction

In this chapter I present the analysis of the findings of the text, which aims to capture the main themes that have emerged during the hermeneutical interpretation. These themes reveal the intersubjective meanings of the experience of chronic primary pain, understanding the lived experience of the participants within a shared field of experience

This analysis was a phenomenological exercise and, as such, assumes a posture whereby it is important to recognise that this is one description of human experience and therefore one interpretation. It also assumes that, as a single interpretation, it will never rule out the possibility of other, perhaps richer or complementary, descriptions (van Manen, 1984). As well as being an interpretative endeavour, the analysis was a thoughtful and reflective exercise aimed at identifying the essence of meaning, trying to remain anchored in the experience of the participants.

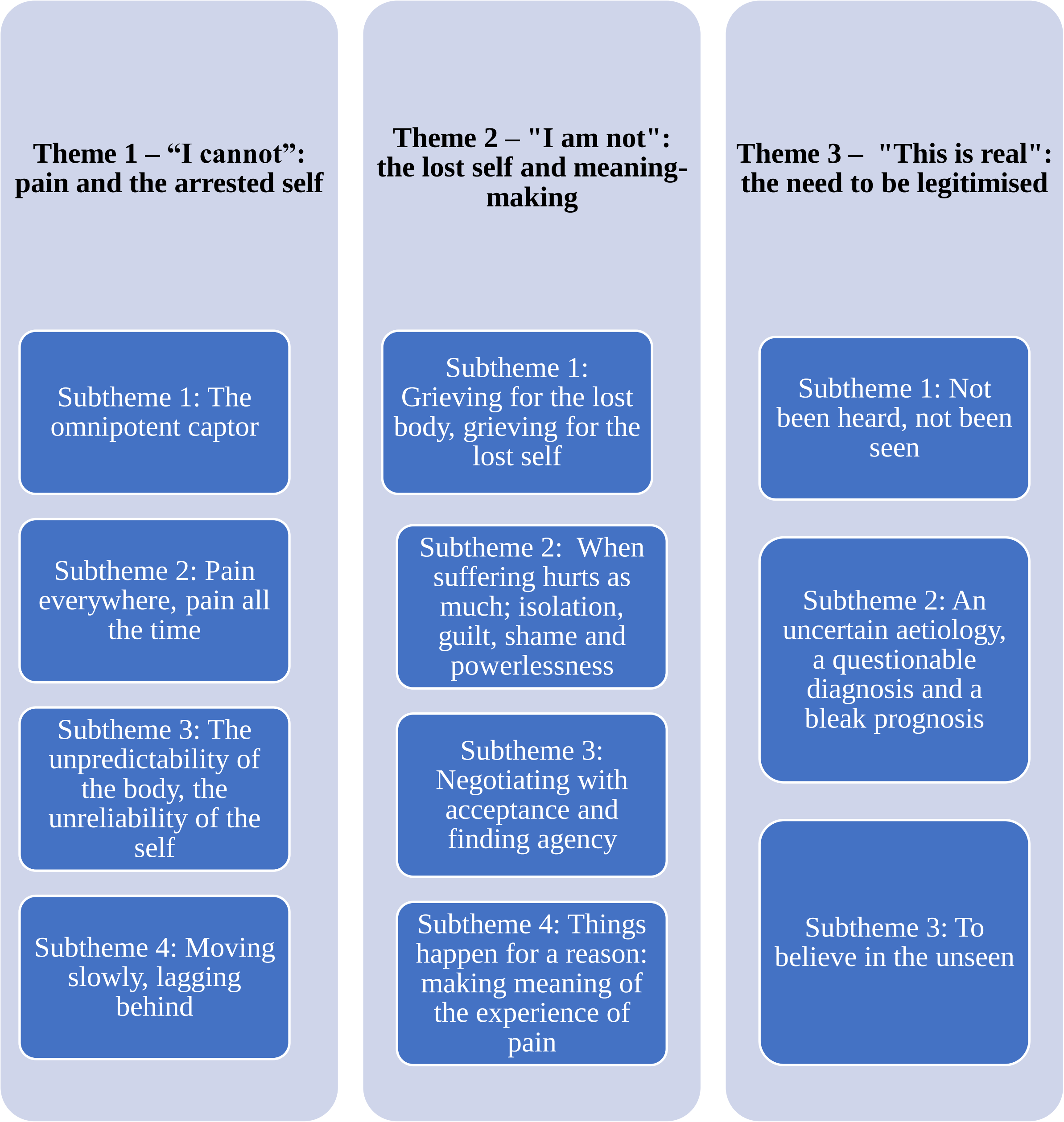
By zooming in and out of the text, and going back and forth between the parts and the whole, the subjective and the intersubjective, I let the material speak, remaining open to different interpretations until I was able to "capture" general themes that I felt did justice to the participants' experiences.

Three overarching phenomenological themes have been set out, each made up of subthemes

(Figure 4). These themes can be understood as the knots of our web of experiences (van Manen, 1984); as such, they are interconnected and overlapping, and together they make up a universe of meaning. Furthermore, having intersubjectivity as the locus of understanding, the themes revealed that chronic primary pain, as an aspect of the lifeworld, is both transformed by and transformative. As we can observe in themes 1 and 2, chronic pain disrupts the way the women experience the world from the place of the body and the lived body, changing the way they direct to the world and others. And lastly, in theme 3 we can observe how their experience of pain is received, constructed and arguably delegitimised by others and their specific situatedness.

This chapter concludes with a reflective exercise regarding the relational encounter with the participants in an effort to demonstrate the reflexivity of the process through which this text was co-created.

Figure 4. Overarching themes and subthemes



Theme 1 – "I cannot": pain and the arrested self

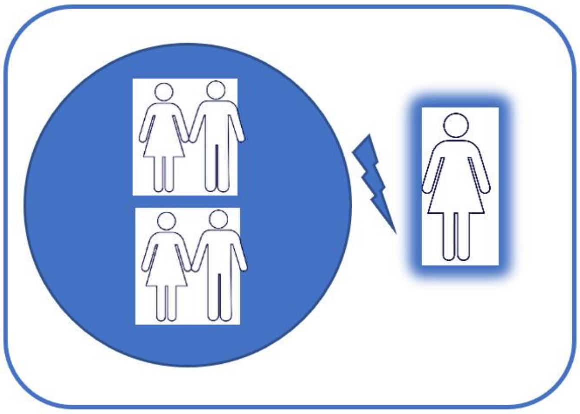
Theme 1 – "I cannot": pain and the arrested self

Subtheme 1: The omnipotent captor

Subtheme 2: Pain everywhere, pain all the time

Subtheme 3: The unpredictability of the body, the unreliability of the self

Subtheme 4: Moving slowly, lagging behind



Overview

This major theme aims to convey the experience of pain as an omnipotent and omnipresent force that comes uninvited and unexpected to the lived experience. Throughout the four subthemes presented, I lay out how pain had the power to bring each of the participants' lives to a halt, forcing them to retreat from the external world, the world of others, and surrender to the pain demands. Their way of being-in-the-world was characterised by the lived experience of *"I cannot"*. The world kept existing around them but they no longer felt part of it when in pain. The accounts transmit the idea of a self that has been captured, chained and bounded by pain. The cell that the pain-bearer inhabits is their only reality and imposes the boundaries and limitations of what they are, were and will be.

There is no escape from pain, which is always present, whether subtly or forcefully, in their bodies and their minds, in their lives and, subsequently, in the lives of those around them.

Subtheme 1.1: The omnipotent captor

During our conversation the participants conveyed an image of the pain that can be described as a kind of entity that was robbing the self of its being. Within its invisibility and with its concealed weapons, pain harms and abducts the self. When talking about their pain, it was as if they had been abducted by it, and their feelings of powerlessness and helplessness were a common feature for all participants.

Being in pain, constantly, chronically, left them feeling drained, as if the breath of life had been taken away from them, feeling depleted and exhausted. Maryam's feelings of helplessness are represented in the following:

> Yes, energy, I don't have that energy. I get up in the morning and I don't even want to go to the bathroom. I just find it too painful; I'm just dying to release myself. I can't and I go back to bed again, and I struggle.

This follows the idea that there is an element of distrust about their bodies and the way that pain will behave. Initially, it is difficult to establish what the balance is between doing, not doing and doing too much. Sometimes, doing too little, or the lack of activity, can increase the feelings of pain and stiffness, when on the other hand, trying too hard and pushing their boundaries can have terrible consequences for their pain experience. In the same manner, most of the participants shared that pain was not always the same, was not always in the same location and did not always feel the same. This was mostly in the case of participants with a diagnosis of fibromyalgia, where pain can be experienced in myriad ways: sometimes it is localised and sometimes systemic, sometimes pounding, sometimes stabbing. It was shared by most participants that pain behaves as having its own life, having a slippery and cunning nature, wearing a confusing disguise. Nataly felt confused by her fibromyalgia pains, which, in turn, made it hard to describe them to others: “So it’s almost like you have a primary pain but then you have all these secondary pains, which just… Sometimes I don’t know what starts what.” This made some of them feel alienated from their pain, as something that first does not belong to them and, second, does not respond to their efforts to control it. It is an engulfing experience that happens to them, without their participation and, worst of all, at times without explanation. The frustration of the interruption of pain, which presents as an uninvited guest, was also a theme that was observed in the accounts. The power that pain has to stop everything around them, whether it is work, a walk in the park or a conversation with friends, is always experienced as disruptive, a killjoy that comes and robs them of the experience of engagement with life. Pain demands full attention and everything else needs to be dropped on the spot. Pain does not wait to engulf. As Dorothy shared: “And obviously, this was sucking in my life, sucked in work, even if I wanted to see my friends I couldn’t because I was in so much pain with my stomach.”

Elena felt the interruption of pain during our interview and also described her need to remain silent, as if pain were also demanding discretion:

> I had this pain when I was talking to you, you feel like somebody is stabbing you, it feels like stabbing and somebody is turning the knife slowly. But before, I didn’t know what it was so I used to do this OOUCH! Fuck, AHHHH. Now I don’t do it anymore, now I stay quiet.

What Elena said provided an insight into the disruptive aspect of pain, but also its silent and invisible nature, which, although felt with intensity by the pain-bearer, remains unseen by the other, a theme that will be developed later during the analysis of the findings.

Some participants described the physical imprisonment of their bodies, feeling trapped in pain. There is a consensus that pain has the power to paralyse the person, which was commonly referred to by the participants as “feeling stuck”. There are different ways of feeling stuck: this could be a jammed kneecap or an aching nerve or for others the inability to get out of bed.

There have been times when they dared to disrespect pain's supremacy. The punishment for ignoring its power over them has shown them that whenever they decide to take a risk or ignore the ever-present threat of pain, there will be a high price to pay for this audacity.

Participants reported how, on many opportunities, they were aware that they were pushing the boundaries but it felt worth it. They have to live their lives and, at times, they are willing to pay the price, a high price indeed.

Toni, spoke about the importance of being with her grandchild, how this provides meaning in her life and how she is willing to pay with pain for these moments of connection and love:

> I can only do two things in a week and if the possibility is to do it with my children and grandson or someone else, I'm gonna pick my children because it's just more worth it to me. Like I'm happy to push through the pain, push it, push it, push it and do something nice with them and then I'll pay for it later.

Jane described how she made the conscious decision to ignore this constant threat of pain in her life in order to have a memorable day with her family in an attraction park during a holiday. She was certain that pain was the currency for enjoyment and sharing with her loved ones:

> I know I'm gonna be in too much pain tomorrow, 'cause I was like on a high going around. I knew I was going to be in too much pain the next day (…) by the time we got back to where we were staying, I was in so much pain, and I woke up the next morning and I was like, "I can't go anywhere, I can't go out, I'm in too much pain, I need to stay in bed".

The omnipotent quality of pain leads in all the accounts to a withdrawal from the external world. When the women felt the pain, they felt forced to retreat to the realms of their bodies and the different physical sensations and emotional despair imposed by pain.

With its invisible hand, pain grabs them and takes them to a corner, forcing them to retreat from the external world and receive their full undivided attention. As Toni stated: "When I'm in so much pain is like everything goes blank and, literally, all that's there is pain and I can't think of anything else, I can't do anything else, the pain has just taken over."

The analysis revealed that being in pain is, in a way, incompatible with being there for another and with another. Pain presents to the participants like an imperative, whereby every physical, emotional and cognitive effort has to be directed towards the self.

In Nataly's account, when finding herself in intense pain she will immediately withdraw from the external world; when she is with others and pain comes, she just halts, stops talking, stops engaging, stops being present for others and the world and a part of herself is silenced. This is something that she does not recognise in herself: the quietness, the withdrawal, contrasting her extrovert and talkative identity. She stops engaging with the world because she has gone inwards to be with her pain; there is no room for other thoughts or feelings that do not belong to pain.

For those in pain, the world narrows down to that experience and everything else seems out of focus, far in the periphery, like in a parallel world they are unable to reach. Others are there, yet the pain is taking the self away from them.

Elena talked about how when she is in pain, she finds it hard to concentrate on anything else, which, as expected, has an impact on the way she relates to others: "I can't do anything anymore; it's almost like we go somewhere, I need to have a place to stretch my legs, otherwise I cannot concentrate on what the other person is telling me."

For Ruth, as well as other participants, when pain comes, it is like pressing the pause button and everything needs to come to a halt; no matter where they are or who they are with, they can no longer be there or exist for another. There is no room for anything or anyone else other than pain, only the feeling of an arrested self. She expressed her sadness at the fact that she cannot be present for others when in pain since she feels forced to retreat to her own self:

> Hmm, well, yes it's quite painful, it's quite… I feel quite sad about it because it makes you, you know, go back into yourself, because the pain is there and you can't concentrate on doing something else somehow (…) I can't concentrate on being with the other people so is not always quite easy. In a way, I rather spend time with myself…

The way that pain interrupts their relationship with the world, and the world of others, has had a profound impact on their relationships and their potential to have them. Little by little, pain has been eroding their social world, leaving them isolated and anxious about the few relationships they have left. The loss of identity has impinged on their sense of belonging; they are not the same social beings they used to be and they are eventually cut off from their circles of friends and family. This is clearly illustrated in both Elena's and Toni's accounts:

> (Elena) Because people knew me differently, on my bike, exercising, cooking, festive, big parties, dancing, motivating everyone. Now it's the opposite. I'm on my own, I don't go out. My friends don't even call me to invite me anymore; they say, "Every time we invite you, you don't come."
>
> (Toni) When I got diagnosed from Uni, I had quite a few people that I used to talk to; they would invite me out and I said yes, then last minute said no, 'cause I couldn't, or just point blank no, I can't make it because of this. So, in the end, that kind of fizzled, people stopped asking me to go out, people stopped messaging me, so I kind of lost a lot of my friends.

Maryam, who had been in pain for a long time, had been through this loss, and although she would have liked to have people around her, she knew that she did not have the physical and emotional energy to engage in a relationship. She feels completely isolated and, like many of the other women, her main relationship is with her pain, her sole and most intimate relationship. Nataly felt that her relationship with her husband had to be reassessed when she began to realise the extent of her chronic condition and her long-term needs:

> Essentially, you know, is this the person who is going to care for me if I get bad? Or is this the person I even want to be with when I get bad? Like, is he going to be able to... I have had all sort of, I really thought that we were not going to stay together. But then I did go through phases when I felt very negative about the relationship, what shall I do and that.

Jane, on the other hand, finds it difficult to envision a romantic relationship, knowing that her health problems may be an issue:

> But I say to myself, I'm in too much pain to be in a relationship… Like, I can't see myself being with somebody. The person would have to be extremely empathetic to put up with the pain I'm in. I can't

> see him doing that.

As has been observed in the different accounts, being in pain means having to submit to its demands, to stop, rest and retreat. Mind and body are engulfed by pain. Everything else needs to be abandoned, immediately; there is no room for negotiation and no choice when it comes to deciding when the best time and place to feel the pain is. This means that, when in pain, it is almost impossible to engage in a meaningful encounter with the world beyond pain; the self, therefore, has to retreat to her own private world of agony and isolation.

Subtheme 1.2: Pain everywhere, pain all the time

Pain has the quality of being present everywhere and all the time, inhabiting mind and body, enslaving the self in a state of inner presence that taints both the past and the future.

From the transcripts, it was possible to observe that pain is both a sensorial and affective unpleasant experience, recognised as an ongoing presence, impossible to ignore. And, as a part of their identity, pain was a presence that followed them wherever they went, casting a shadow over their lives and the lives of others around them. Jane states:

> I am never really not in pain, to a certain degree (…) And even when I'm having a good day and I can go and do different things, when touching my arms, my thighs, my neck, it hurts, it aches (…), is not that I have pain and then back to normal. Every day is pain.

The pain was present in their different facets and roles in life; pain does not make exceptions. There was pain when being a mother, there was pain when being a teacher, there was pain when being a wife, a friend, a student. The pain was present during the day and during the night; it pervaded their waking hours and their sleep. The latter was poignantly represented in Maryam's words: "(cries)… Yeah, I can't do anything, you know. Walking is a pain, talking is a pain, eating, even if I eat (cries) (silence)… even when eating (…) It hurts me so bad, you know, just the act of eating."

And similarly, Toni:

> I just want to function, I want to be able to wake up, go and have a shower and not be in pain every step of the way, standing, sitting, lying down. It's not like I'm fully fit and fully able, and then I go and ask for drugs or something, I am in pain constantly… (cries).

As conveyed by Toni and Maryam, pain is, for most participants, normality. Pain is familiar and perhaps the only certainty that they have. It is an experience that, although they wish it were not there, they know will be the first thing that they feel every morning when waking up. Pain is the song their bodies sing with every breath and every step.

Pain, in many cases, is omnipresent in their bodies, widespread through every one of their cells. The majority of the participants had a diagnosis of fibromyalgia, which means that pain is systemic and their bodies ache all over: muscles, joints, bones, skin and other organs. Pain is not reduced to one part of their body; it is felt everywhere. In the case of Jane, Nataly, Toni and Maryam, as well as having fibromyalgia, they also suffered from conditions such as carpal tunnel syndrome, iliac vein compression, migraine, temporomandibular disorder, plantar fasciitis and IBS, which made the pain experience more complex, difficult to assess, diagnose and treat, as reported by Toni:

> So they are helping [painkillers] but it's just, it's still really painful, everything is like, "Oh my gosh"; from my head to my toes, it's just everywhere. And I think, "Please let me have just the one thing, one illness, one little part of the body and then I can deal with it", but this affects every single part.

Toni felt the omnipresence of pain in her body, its relentlessness and the frustration at having to deal with different conditions and different pains on a daily basis. It came across in the transcripts that the participants who experienced this multi-focal pain were aware of the chain-reaction style of pain behaviour. They spoke about how one localised pain triggers another one, and then another one, until their whole bodies ache. This was exemplified by Nataly when she spoke about her toothache, which eventually extended to her jaw, neck and the rest of her body. She referred to pain as a "creeper", as something that has a life of its own.

Ruth referred to her experience of how pain takes over her body. It might start somewhere but then, in Nataly's words, pain "creeps" over her and she is no longer able to identify where it hurts and where it does not. She spoke about her frustration when her systemic pain is met with a reductionist gaze from healthcare practitioners, who, in her opinion, sometimes fail to see the whole picture or acknowledge that pain is present everywhere: "You know some people ask you 'Is it here?' 'Is it there?' And I'm thinking but I'm not so sure, sometimes when the pain is so painful you don't really know where."

The women spoke about how the pain inhabited not only the body but, insidiously, also the mind, turning it into a pain-thinking mind. The thoughts of a pain-bearer are also limited by the boundaries of pain: the planning, the anticipation, the possibility for alleviation, the dilemma about medication, and so forth. Dorothy reported that it was really hard to think about anything else and the pain was always in the back of her mind; she described feeling that her life revolved around pain and the dilemmas presented by medication. When not thinking about pain, Dorothy spent her time thinking about pain management and her complex relationship with medication and how at times she had to choose between the lesser of two evils. Having a promising career, Dorothy's chronic pain was seriously jeopardising her future; understandably, she could not concentrate and started to make mistakes at work. With no other option left, she resorted to strong painkillers to keep the pain at a tolerable level. But, with her pain under control, Dorothy had to face another challenge:

> I was taking my painkillers and the problem with them is that they make me feel very drowsy and I lose concentration and they also give me stomach ache but I can't do anything because that's the only thing the doctor can prescribe me. (…) Because I took a lot of time off work, I was in that situation a lot and even with the co-codamol they gave me, it helps but the side effect of that is that it makes me feel very drowsy.

For Nataly, the awareness of pain is always there; even when pain is dormant, she knows that it is still there and its silence is only temporary. Even when pain is not the main protagonist in her life, she knows that it is still there; even in its quietness, she knows that pain is alive, ready to strike:

> You can’t get rid of it [pain] so yes, it’s almost like you feel some form of streptococcus in your blood and it just kind of lingers and now and then decides to become more of a nuisance and then it goes to sleep, it is sort of like that.

This is an important aspect of chronic pain since it is not only present during flare-ups; pain is a constant presence in sufferers’ bodies and minds and it only takes awareness to realise that it is there, sometimes tamed and under control and sometimes really loud and wild.

For most participants, their experience of chronic pain started many years ago. A pain that long ago was specific, localised and manageable has, over the years, become an unstoppable force that has invaded every inch of their bodies and also their biographies. Pain has become their identity and – despite its debilitating nature – what they consider normal.

Ruth spoke about how pain is a part of her life and tried to take this with a bit of humour too: “We make a little joke, ‘pain of the day’ with me (laughs) because there is the ‘Thought of the Day’ on the radio and the programme is ‘Pain of the Day’ so we take the mickey out of me…”

The pain is a constant – although not necessarily consistent – presence in the participants’ lives. It is a presence that has taken over not only their bodies but also their minds, their past and their future. Their pain has succeeded to conquer every aspect of their lives, and even in its quietness it can still be felt.

Subtheme 1.3: The unpredictability of the body, the unreliability of the self

The behaviour of pain in the experience of chronic pain was described as hardly predictable by the participants. Although, at times, they felt that it was possible to take some measures to prevent exacerbation of the symptoms, pain presented itself at a time and place that could barely be predicted by the pain-bearer.

The unpredictability of pain, and subsequently their bodies, is not only about *when* and *where* but also about *how*. When patients described their flare-ups, they spoke about their feelings of not being in control of how pain presents and how long the pain will last; they do not know whether this flare-up will be manageable or it will mean them having to stay in bed for days. They also do not know whether the medication will work or whether they will despair trying to tolerate the intolerable.

Something fundamental has been taken away from them. The (relative) certainty that they had about their bodies – waking up, getting out of bed, having a shower, walking to work, sitting at their desk, going to the gym, and so on – all that has been taken away by the experience of chronic pain, as was the case for Jane:

> Yes, funny, 'cause years ago, I liked to plan everything, I like to know what I'm doing. (…). 'Cause now I'm the complete opposite. I have to do things on the spur of the moment. I can plan something and then, if I'm feeling good, we can go and do this but I'll let you know on the day.

And it is the not knowing that has created, for many of the participants, feelings of powerlessness and frustration, which relate to their shared experience of anxiety about their own bodies in pain and how these will impinge upon their lives and the lives of others. Ruth came to the realisation that it is the lack of control over pain and how pain manifests in her body that create most of her suffering:

> I mean, is the fact that it comes insidiously in your life, without you knowing it, and sometimes you don't have the control of it, and that's the thing, is the lack of control, I suppose, that is the most painful thing and talking about it … yeah … makes me realise that's the main issue really, is the lack of control of your own body.

Accounts about pain and its insidious nature conveyed the idea of pain as a dormant volcano, and the feeling of threat is ever-present; any movement could wake it up, make it angry, heated and explosive. Even when having a "good day", which means manageable levels of pain, the participants talked about their need to live with caution and not take advantage of these infrequent windows where pain seems to give them a break.

When life is dominated by the type of pain that is not only unpredictable but also very difficult to diagnose and treat, the participants felt that their relationship with the future was rather problematic. The frustration of not being able to plan and having to cancel plans last minute was a constant feature in their lives.

The excitement about the future and the possibility of fulfilling life projects is usually mixed with anxiety about not being able to do it. Travelling was a common example among the participants, and it was apparent that their excitement about holidays was mixed with high levels of anxiety about the high chances of having to cancel their plans at the last minute. Most participants mentioned that they have been forced to live in the moment, in the present, which is not necessarily a philosophical decision but a way of being that has been imposed on them and not necessarily embraced. As Nataly expressed: “It is like day by day because I don’t know how I am going to be in 10 or 20 years.” And Dorothy: “I’m just taking every day as it comes. I can’t really plan for the future.”

For the younger participants, the threat of pain was inevitably projected onto their future, not only plans and travelling but also their deep desires. Although they consciously tried to avoid thinking about what the future holds, they felt that pain had already tainted their futures. As Vanessa mentioned: “What I want and what I see, they are two different things.”

They are aware that their wanting, their capacity to think about the future, is limited by their condition. As Vanessa mentioned, they can aspire to do many things but they know that the reality of their bodies will eventually dictate what they can and cannot do.

The existential uncertainty felt amplified in them when they connected with their deep anxieties about life projects that perhaps had already been fulfilled by older participants. With their futures lying ahead, their plans to have a family, develop further in their careers or consolidate a relationship felt distant, uncertain and mostly unattainable.

As well as their plans and dreams, it is important to bear in mind that their futures are also inhabited by others. The natural assumption that people will behave in an anticipated and predictable manner is challenged by those who suffer from chronic pain. The intersubjective implications of their unpredictable bodies are not to be underestimated, since, according to the different accounts, they will inevitably have an impact on their relational world. It was shared among all the participants that the erratic features of their pain, and the inability to guarantee their commitments, made it hard to make plans with others and for them to feel trustworthy, as was the case for Nataly:

> Also, I had to cancel lots of things because I can't plan; I can plan for some things, but I can wake up on Sunday and I don't want to see anybody. Or I'm just too sore, I had a horrible night, so it can be hard. I do find that some friends can be a bit … they are kind of listening but they are not hearing me (…) It's very difficult to explain to somebody who hasn't gone through something like that. I don't know what I'm going to feel like in five hours, never mind in five months.

Ruth spoke about the time she became unwell before going on holiday with her husband and children. She was the only one able to drive to their destination and the family had to wait until her symptoms eased. Many weeks passed and she was still bedbound:

> The fact is that obviously, I was frustrating others as well, so it was quite … it was a difficult situation to be in because they were waiting for me, to get better to go on holiday, and it never really happened.

Like many other times, she felt powerless, unable to offer something, some kind of certainty or reassurance to her family, her heart aching along with the rest of her body.

Participants also reported that when making plans with others, on many occasions the unpredictability of their symptoms has led them to cancel, making them feel guilty and ashamed. For Elena, the unpredictability of her pain has had serious implications for her ability to work and have a stable financial situation: "And because I am not 100% well, so many times I had to cancel; if I were in a full-time job, they would have sacked me three, four times."

And Toni:

> I feel like if I was an employer, I would find it difficult to employ me because I know that everything changes so rapidly, I could be completely fine one minute and then you come to me two minutes later

> and I am *(panting gesture)*.

As well as the way their bodies respond to pain, the participants spoke of having to deal with another form of uncertainty that stems from receiving a diagnosis that at times feels devoid of meaning. When given a diagnosis of fibromyalgia or another form of chronic primary pain, where the pain is not the diagnosis but, disappointingly, the prognosis, the participants are met with the uncertainty of health professionals who cannot say much about their condition, what is causing it and how to treat it. As Jane states, her condition is a diagnosis of exclusion, where no test can confirm that she suffers from the illness: "He [physician] said 'I think it's fibromyalgia cause there's no blood test or anything to show that you have it'."

They have been told that they will have to live with their pain. Living with this knowledge means that they do not know what lies ahead of them, whether their bodies will be able to cope and whether they can withstand the uncertainty of their condition.

Maryam said that sometimes she feels that suffering from a chronic pain condition is almost worse than cancer, as there is no cure and there is no respite; it is just ongoing torture. So, pain is their sentence and they feel that this one is for life.

The unpredictable and fluctuating symptoms of their pain conditions led, in all the accounts, to feelings of powerlessness. This meant that planning and thinking about the short- and long-term future became not only frustrating but also pointless. The limitations imposed by their bodies and the erratic behaviour of pain have inevitably affected their relational world, where they no longer inhabit the shared space of certainty and reliability.

Subtheme 1.4: Moving slowly, lagging behind

Chronic pain, as described so far, has had an important influence on the participants' relationship with time. It is the chronicity, the duration in time, that inundates the pain-bearer's relationship with the past and future. As has been stated before, their relationship with time, in this sense, has been forced into the here and now, the experience of present pain.

But beyond their relationship with time from a past/present/future perspective, their internal time has also been altered; the tempo and pace at which they move and think are experienced differently and there is an inherent slowness that they do not recognise as theirs, which has been imposed by the limitations presented by pain and associated symptoms.

When in pain, the self moves at a different tempo. In all the accounts, the experiences of being in a body in pain evoked the idea of wading through molasses, having to go slow, constantly fearing getting stuck. Following the idea of pain and being incarcerated when in pain, the subject moves as if dragging a weighted chain behind her.

Getting to the desired destination seemed, for Vanessa, like an ordeal that took a lot of time and effort. Every day, every task took place in this thick bog: "My life before was to get up and get ready; it didn't take much of an effort to get ready. Today it was a struggle, to shower, to do my make-up."

When talking about what it means to live in a body that hurts, the participants reflected on the idea of how they need to move slowly in order to keep pain at bay. If they do not abide by this new sense of time that is needed for their new bodies, then the pain is awakened. Many examples could be extracted from the accounts. For participants like Ruth, the experience of driving to a usual destination needed to be reconfigured. A commute that used to take her 30 minutes to drive needed to be recalculated under her unique lived experience of pain, thus allowing herself 3 hours to get to her desired endpoint. Elena spoke about her experience with gardening, how she used to enjoy doing her garden and how efficient she was at it. A task that used to take her a couple of hours in the past now takes her days. The same was experienced by Vanessa and Maryam and how they felt about tidying up their place, how a weekly task that used to take a couple of hours now needs to be spread out and broken up into mini-tasks throughout the week. And of course, this is only assuming that they are well enough to do this because there are times when even small tasks seem unachievable. When the latter happens, their to-do lists get bigger, as do their feelings of frustration, inadequacy and guilt.

The women spoke about how going slow is caused by their mobility restrictions, such as pain while walking or other movement, but also by their extreme fatigue, another symptom of fibromyalgia and chronic pain conditions. Most participants spoke about their tiredness, due to their fibromyalgia or the sleepless nights caused by pain. It was a common theme, the struggle to find the energy to do things, and, despite having the motivation to engage with the "doing", their bodies, more often than not, simply let them down. There was a sense that their sluggish bodies are also the result of their fight against their pain, which feels like psychological fatigue, the result of feeling depleted of energy to carry on. And, like everything else with pain, they described the need to watch out for tiredness because it also has an impact on their pain, as was the case for Toni: "If I go out, I know that I'm going to feel it when I come back, and when I'm really tired, when I get really exhausted, the pain seems to be heightened."

Through the accounts, it was also possible to observe the shared feeling that their newfound tempos did not match others, which made them feel inadequate, translating into a separateness, a feeling of not belonging, of dragging behind in the race of life. Most participants referred to the experience of walking alongside someone, and they could feel their struggle to catch up with their walking partner's pace. They were aware that their walking was slow, it needed to be slowed down, and they needed to pause and give their bodies a break before they carried on. And they all expressed the need to feel understood and met at this new pace and that going slow was not only a limitation but also what they were required to do in order to keep pain at bay.

Maryam spoke about her feelings of inadequacy when doing her shopping, the awareness of her slowness, of not being able to mirror the pace of the rest of the world:

> Or when I am in the queue or go shopping, I want to empty the trolley and I am extremely slow.

> Sometimes I can’t hold objects or drop things. People behind me usually say, “Hurry up, hurry up, what’s taking you so long?”

And it is not only their bodies that behave in this slow-moving fashion; their minds also struggle to catch up with thinking at times, as was expressed by most participants, especially those with fibromyalgia. The brain fog that prevents them from focusing and thinking clearly makes them feel like their brain is working in slow motion, unable to catch up with conversations or specific tasks.

On many occasions the participants became aware of this during the interview; they would get lost or forget what the questions were, and they reported that this was a common issue in their lives and spoke about the familiar feelings of failure and shame when this occurs. This happened to Nataly during our interview: “… now I forgot what I was going to say. This is another thing that happens to me a lot. I just, I feel like sometimes I’m a bit stupid, I don’t know what we were saying.”

In this sense, the pain-bearer, according to these findings, feels betrayed not only by the stiffness and slowness of her body but also by her mind, which lags behind. Maryam felt that it is not only the physical limitations of pain that have affected her career and ability to work; her decreased and *slowed* cognitive functions such as memory and concentration have seriously reduced her probability of getting a job. The process of going through a job interview has been not only physically but also emotionally painful, as illustrated in the following vignette:

> I can’t concentrate, there is a loss of memory, I can’t put the answer to the question, with a lot of them in fact, they feel sorry for me, I know that it would be harmful if they give me the job, they see that and they think that maybe it is best not to have a job, but I don’t know.

Finding themselves wading through life, the participants felt that they were physically and mentally unable to catch up with the speed of the world. The pace of other bodies overtaking theirs, and of sharper minds getting ahead of them, leaves them behind, alone and abandoned.

Theme 2 – “I am not”: the lost self and meaning-making

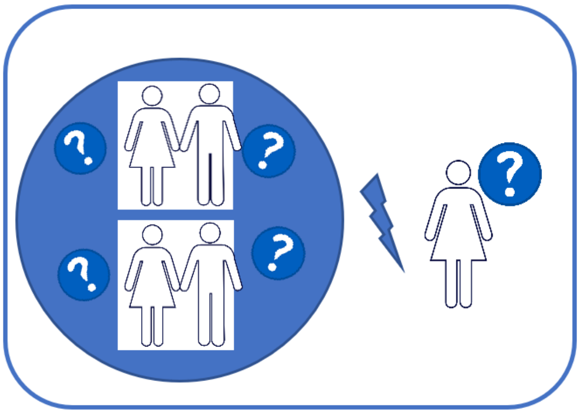
Theme 2 – "I am not": the lost self and meaning-making

Subtheme 1: Grieving for the lost body, grieving for the lost self

Subtheme 2: When suffering hurts as much; isolation, guilt, shame and powerlessness

Subtheme 3: Negotiating with acceptance and finding agency

Subtheme 4: Things happen for a reason: making meaning of the experience of pain



Overview

The second overarching theme is a more detailed description of the way that the experience of ongoing chronic pain has a profound impact on the participants of this study. Their bodies, which have changed dramatically, have inevitably changed the way they exist in the world, and the way they exist for others, which has led to a multi-layered loss whereby different facets of the being are now gone. Their lived experience of being-in-the-world is characterised by navigating the reality of *"I am not"*.

Loss and grieving for the old self and who they were for others were not the only emotional experiences described, since the experience of chronic pain is also accompanied by the intersubjective aspects of isolation, guilt shame and powerlessness. These emotional experiences are not to be overlooked, since they are responsible for deep psychological suffering, which has seriously affected the lives of the participants, having their own reality and imposing new challenges and needs.

This theme will also cover the fact that, despite – or perhaps because of – the challenges mentioned above, the participants have found their own resources to open up to acceptance and take responsibility for their well-being. In the process the findings also showed that the participants used this openness and a newfound sense of personal agency to connect with something larger than them: a sense of purpose or meaning, something to hold onto in the midst of uncertainty and despair.

Without a doubt, the experience of physical chronic pain carries with it intense psychological suffering. The despair conveyed in the accounts is the result of the ongoing experience of isolation, shame, loss and anxiety, among others.

Touching rock bottom has led most of the participants to get in touch with a different aspect of their existence, questioning the meaning of their pain and their lives. Through this enquiry and encounter with the most vulnerable aspects of their selves, it is possible to reach a place of acceptance and the possibility of connecting with their newfound sense of personal agency in a journey that has, so far, been characterised by feelings of powerlessness, meaninglessness and despair.

Subtheme 2.1: Grieving for the lost body, grieving for the lost self

Having a chronic pain condition means having to inhabit a body that is no longer recognisable by the pain-bearer or those who bear witness to the way they have changed. The feelings of alienation from their bodies were a common theme among the participants, who described struggling to reconcile the mental image they have of their bodies and what they can do with them within the reality of their limitations. The latter leads to a profound loss of identity, altering the self-image they had from a time when the pain did not dictate their lives to the self-image of a now disabled, incapacitated self. There seems to be a fragmentation between the body and the self, a loss of attunement between these two realms that forces the pain-bearers to reassess who they are and who they can be within their physical limitations.

Toni and Jane felt betrayed by their bodies, which are now an obstacle preventing them from achieving their purposes and carrying out the actions that are part of their identities. Pain comes between intentionality and the world they can no longer reach. Their bodies have lost strength and stamina, and they inhabit a frail and disabled body that does not match the definition they used to have of themselves. As Toni expressed: "Like I'm 38 and I need people to help me get dressed, it's just … is not a life I want to live."

And Jane:

> I'm used to working out, lifting weights at the gym, and for me to come down and have to do lighter exercises, it's hard. That's not who I am. So, I feel like I'm forced to do something that I don't want to do. I am living in someone else's body.

A body that does not belong to them, a body that no longer responds to intentionality and that simply works on its own accord and not in their own service, leads them to experience a profound sense of grief.

Jane, Dorothy and Vanessa, the youngest participants, expressed their feelings of loss when it comes to their failure to do what other people of their age group can do, as Dorothy mentioned: "I can't do what a normal person of my age would do. I just don't have that lifestyle." They shared the experience of a felt age that does not match their chronological age. Despite their youth, their bodies ached, they felt slow, and weakened; they felt both physically and psychologically vulnerable. Jane stated: “Yes, it feels like ... I’m 26, I should be like fit and active and out with my friends, out doing this, out doing that. Instead, I’m at home and I’m in pain.” Jane also spoke about her love of travelling; she spoke about the sadness she experienced when thinking that her plans of taking a year off to travel, like many of her friends were doing, had been ruined by her health conditions. And it is not only their plans that are getting cancelled but also their freedom to plan, their freedom to think about an imagined future that, as young individuals, could be filled with possibilities and opportunities. They have lost, in other words, the possibility to dream.

Throughout the accounts, it was also possible to establish that being in pain and restricted by it means the women have lost their sense of worth and capacity to contribute to the world. The previous roles they held, within their own families, communities or societies, have been deeply affected. By retreating to their own private worlds, they feel forgotten and no longer needed.

Because of her aching body, Elena felt she was prevented from “doing”; she could not have an active role in the world in the way she used to have. Elena spoke of her frustrations about the impossibility of finding a job because of the unreliable nature of her pain and how this affected her employability and potential to contribute to the community, as she had done in the past. She now has to live on benefits but continues to do volunteering when she can, which helps her to connect with feelings of self-worth.

> I’ve always worked, so if I had my health again, I would work immediately. I feel like I said to my friend, I feel incarcerated, you know in your body like you want to do and then you get pain and sick.

Something similar was observed in other accounts when it came to specific roles such as being a mother and a carer. Ruth and Elena, both single mothers with teenage children, talked about the difficulties they encountered when having to be present and available for their children but unable to move from their beds because of the pain they were experiencing. They had to help with homework, as well as daily tasks of cooking, shopping and cleaning, and there were many times when they were incapable of fulfilling any of these. The latter is expressed in Ruth’s words:

> But for me, it’s been mainly with my daughter, sometimes I’m tired and I can’t help her with homework or I can’t do this or that; if I want to do the cooking, maybe you need an ingredient and you can’t be bothered to go to the shop ‘cause you are in pain. It’s little details but it does change the texture of your life somehow.

Ruth felt sad and guilty that she experiences this as a failure; she wants to be there fully for her daughter but her body fails her.

In Elena’s account, her pain threatens her role as a mother but also as a carer. Having a child who also has a chronic health condition puts extra pressure on this role and creates a massive fear of not being available when needed the most.

All of the participants who were mothers spoke about how difficult it is to be a mother while also being in pain. They are aware that their children are their priority but when pain makes an appearance, demanding their full attention and limiting both their bodies and minds, they feel powerless and helpless. However, despite this pain, they are aware of how much they push through their pain over and over again to look after their children and fulfil their parental roles. This was the case for Toni: “It’s actually hard to say. I think that with women, especially when we have children as well, we try to put it to the back a bit, you try to carry on as much as you can.”

But, as previously discussed, when pain calls, it is almost impossible to ignore it, which makes motherhood a challenging competing demand.

As well as withstanding their pain, the mothers also felt the need to conceal their pain and suffering from their children in the hope that they would not become overly concerned about them. Eventually, this adds another level of pressure, anxiety and loneliness.

And those who are not mothers shared their anxieties about not being able to fulfil the social construct of a feminine identity, whereby they should be able to procreate and care for a child. These feelings were shared among the younger participants, who had conflicted feelings and opinions about the potential to become mothers.

As Jane stated:

> So, I think it would be selfish for me to have children where I am now. Especially because [it] is not how I want to bring up my child. I can't envision it, because the pain is stopping me, and how am I supposed to bring them up?

As well as her anxieties about her capacity to raise a child when in constant pain, Nataly spoke about how pain has led her to mistrust her own body, and with the high levels of unpredictability about her symptoms and her pain, the idea of pregnancy and childbirth felt threatening and hard to imagine.

It is possible to say that the experience of chronic pain carries with it different types of loss: loss of their old bodies, roles, relationships, independence, financial stability, jobs, dreamed futures and possibilities. Chronic pain has forced them to live a restricted, one-dimensional existence. For most participants, navigating these losses, and the grief associated with them, has been a complex process that, in most cases, has had a negative impact on their lives. As expected, there was a resistance to accepting that their bodies, their identities, have changed in such a profound way, as was the case for Toni:

> And I have to grieve for the old me, who used to be very active and loved the gym and loved to work and go out with the kids. I have now to change my whole way of thinking and my whole way of doing things.

It was observed that pain has inevitably imposed a new reality and forced the women to redefine who they are and who they can be for others. The identity that has been personally and interpersonally constructed throughout their lives has been tainted by pain. Inhabiting a body that they struggle to recognise and reconcile with, the participants also feel they can no longer be the person they are supposed to be, an inevitable loss that they have had to encounter and a loss that is also shared with those around them.

Subtheme 2.2: When suffering hurts as much; isolation, guilt, shame and powerlessness

It was observed and experienced during all the interviews that physical chronic pain was always mirrored with deep psychological suffering, which was, in many cases, as intolerable as the physical pain itself. This suffering was complex and multi-layered, where the different elements are difficult to untangle.

As well as navigating the different losses encountered as a result of their chronic pain conditions, other intense and difficult emotional experiences were observed in the accounts.

Like most chronic health conditions, chronic pain can be an isolating experience. When pain affects their relationships with friends and family, the participants feel that they end up living in a world that gets smaller and smaller, and the isolation only increases their despair. As well as this loneliness, the experience of chronic pain also leads to an existential aloneness, which is illustrated in Nataly's words:

> I get emotional because it just, I feel sometimes alone and you know people have different things. I am very fortunate that I have parents and you know, people around me who understand, but unless you go through it, you can't really understand it and you know it's a bit scary and it's lonely.

As has been mentioned before, being chronically ill was linked in many of the stories to deep feelings of guilt that stem from the women's inability to fulfil specific roles within the family or at work, or the fact that they cannot be there for another when needed. Ruth, for example, talked about feeling guilty about her colleagues, who had to cover for her at work. She felt it was okay in the beginning, but later she felt that her absence was starting to impinge on other people's lives.

Although not openly spoken about, shame was inferred from most of the accounts, with all of the participants referring to feelings of inadequacy and inferiority, which have been caused by their physical limitations, as expressed by Maryam:

> I know that I have physical pain, and emotional pain, but I feel I don't want to do anything. And you have a sense of guilt (…) It's just within you that you say, "Oh my God, you must be so lazy", you

> know, you just say it to yourself, and you've got so many qualifications! (cries).

These feelings of shame can be triggered by the idea that somehow the women are at fault for getting ill or that they are responsible for their own pain. There was a general concern and fear of being judged by others, which is exacerbated by the fact that their illness is not visible. This was illustrated in Toni's account:

> Just they look at me, my size, I feel like they are judging that … they are not seeing or thinking that maybe there is something actually wrong with her. I feel like all they see is a big fat woman parking on the disabled spot.

Or at times, they felt they had to conceal their pain from others because, in a way, they felt that their sick bodies did not fit what society expects from them. Feeling self-conscious about being constantly ill and in pain, Jane felt it was best to stop talking about it:

> But if I'm with friends, I don't like to say that I'm in too much pain. I don't like it. Unless they kind of somehow know about it. Cause some people would say, "I don't understand why are you always in pain?" (…) like, "Why are you in so much pain? You may be having health issues".

And it was not only isolation, guilt and shame that insidiously affected their lives. As has been described, the nature of chronic pain can create a deep sense of powerlessness and helplessness, where the participants feel they cannot escape the pain. There is not much available to them to fight their pain and they have to rely on others to find a diagnosis and treatment. It was the powerlessness, as well as all the emotions previously discussed, that led Dorothy and Vanessa to hit rock bottom. Dorothy no longer felt able to bear an all-consuming pain that was eating her life away:

> Having to live with constant pain is depressing. I went through a spiral of a really bad depression. I overdosed on tablets because I thought it was just too much for me to live in this way where I need to feel constant pain.

Following this event, she sought psychological help, which she found very helpful; however, she had to stop for financial reasons. Most of her savings were being directed towards paying private healthcare bills, and when the time came to choose between paying for pain injections or psychological therapy, she did not have to think twice.

Vanessa also shared her story of overdosing on tablets and how, for her, the intention was not to put an end to her life; instead, this overdose was the last resource in her desperate need to feel heard and taken seriously. Having experienced constant dismissal by the clinicians, both in primary and secondary care, she hoped that an overdose would help her to convey the message of her frustration and emotional anguish: “I would have never done something like that in the past; I’m a sensible person, I would never … and these two things that I’ve done to get some attention from the doctors proves how desperate I am.”

As well as Dorothy and Vanessa, other participants spoke about their feelings of wanting to end things and finding freedom through death from the life sentence imposed by chronic pain. Although they did not act on their despair, Maryam and Toni also spoke about their thoughts about giving up life and ending their pain once and for all, liberating themselves from the psychological suffering that felt as debilitating as their pain. Maryam shared:

> That means that you are stuck for the rest of your life, you know, living with pain, and sometimes I think you know, the pain is too much. You know maybe it’s best to give up life, you know, do things, end it.

The psychological experience of pain wears the self down, not just through the sensorial phenomena but through all the secondary suffering or psychological anguish that come with it. As well as their chronic health conditions, many participants had mental health problems such as depression or anxiety, which added an extra layer of concern and care needs.

Nataly spoke about her struggles with her anxiety symptoms, which have become a separate issue to deal with. Crippling anxiety was first triggered by her pains and the fear of something going seriously wrong with her health. Little by little, anxiety pervaded every aspect of her life; she became anxious about other things that were unrelated to pain and had to seek psychological help to deal with this.

And, like everything else with pain, the women’s psychological state was also something they needed to keep track of because, in their experience, feeling anxious or depressed only exacerbated their physical symptoms. This was conveyed in Nataly's account when expressing that anxiety and pain are at times part of the same loop:

> So, I'm aware that when I'm anxious and stressed and I know it is affecting my pain but sometimes it is the other way around. So, I might be okay-ish but then I start hurting for whatever reason and then it brings the anxiety 'cause I am worried about it, so there is no … I can't.

Suffering from a mental health condition such as depression and/or anxiety brings an added complexity to the life of the pain-bearer, and receiving a mental health diagnosis can be a double-edged sword. On the one hand, the women who reported psychological distress to their clinicians were referred to psychological services for further support (although the waiting times made these types of referral rather inefficient). On the other hand, carrying a mental health diagnosis can represent an impediment in their diagnosis journey, as was the case for Toni. Before being diagnosed with fibromyalgia, Toni went to her GP with different pains and physical symptoms such as fatigue and cognitive problems. Instead of having a thorough investigation, this complex symptomatology was understood by clinicians as a manifestation of her previously diagnosed depression and treated with antidepressants. Although not entirely reluctant to accept this hypothesis, Toni felt that making these sorts of assumption prevented her from having further medical investigations and giving her an accurate diagnosis.

> First, they didn't even tell me the diagnosis, no, first you are telling me that it is nothing, then that it could be IBS, take this. Then they tell me, oh, you are depressed. I don't know what I went for, but he said, "Oh it's 'cause you are depressed," and he gave me antidepressants.

The findings show that it is impossible to separate the experience of chronic physical pain from its emotional counterpart. Living with a chronic condition of such complexity, which at the same time can be so disabling, will inevitably lead to challenging emotional experiences, which at times can be extremely difficult to cope with. The need for the women to be equally acknowledged, legitimised and attended to was also evidenced in the accounts.

Subtheme 2.3: Negotiating with acceptance and finding agency

All the women's stories expressed feelings of despair as a result of the physical and mental suffering that pain has imposed on them. As previously discussed, feelings of powerlessness and hopelessness were present in all the narratives, and there was also a shared experience of a lack of care and a loss of trust in their medical journeys. Some participants felt that they had exhausted all the resources available within the traditional healthcare system. Over and over again, they hit the same wall and encountered the helplessness of clinicians and the limitations of pain understanding, as has been the case for Dorothy:

> And you feel quite let down by the NHS. You think that it was there for you for treatment and everything and even if you go to A&E, they can't do anything for you, so I just stopped that. There's no point (…) you feel really helpless. Let down. I felt like with any disease, that there would be a treatment. I thought my pain was so under-researched, there isn't much information and there isn't much support available to you.

As has been discussed, the experience of debilitating and disabling chronic pain carries with it enormous loss. With it comes the process of grieving, which is not exempt from its complexities and challenges. Elements of acceptance in this process were perceived in some participants, who spoke about their intention to relate differently to their experience, learning to care for their pain in a different way, their own unique way.

Dorothy was told by her pain doctor that her pain does not have a definite answer and that she will have to continue to try different treatments until she finds one that helps her pain to reach a tolerable level. She has invested a lot of money to get an accurate diagnosis and a suitable treatment. It was through private healthcare that she was able to get an injection treatment that provides temporary relief. She knows that there is something she can do to get a little respite and, although this may cost her a lot of money, it gives her back a sense of control. This has helped her to become more accepting of the idea that pain will most likely be a life companion; however, she still has some control when it comes to the way she chooses to seek and receive treatment: “All I can do now is try to focus my efforts to try to manage the pain and kind of … if I’m not pain-free, to make it very minimal.”

Most participants shared that they have been able to open up to the idea of accepting their pain and living with a chronic health condition as part of their lives. But this relationship between despair and acceptance is an ongoing dance that requires constant renegotiation, and although acceptance is achieved from a rational place, there is still an emotional upset, which Jane conveys:

> So, at times like that, I feel really guilty, then I have to say to myself, I can’t do anything about that, there’s nothing I can do. So, I have to accept it. So, there’s no point in me getting upset. But obviously, there are days that if I’m at home and not okay and I get upset. And other days where I can’t really not feel quite as low. I’m a bit more, not as low. I mean I’m a bit more like, “Okay, well I can’t do anything about that so…’

What was observed in the findings is that acceptance is neither a categorical nor a linear process. Acceptance is ongoing and requires an element of intentionality and openness to explore the pain experience in a different manner. Toni spoke about how acceptance in itself is an ongoing process, always requiring the flexibility and intention to adjust:

> Especially it’s like, the pain is now ... a way of life, is like putting your clothes on every day, it’s part of me. I’m trying to come to terms with it. And every time I think I have, there would be something like, “No, you haven’t.” … It’s like, you haven’t completely come to terms with it, it’s going to be like that for the rest of your life, you have to adapt.

Accepting their pain as a part of them and their lives created a shift from the threat that pain poses to the self to a more open stance, whereby they did not need to fight pain all the time. Instead, the participants were in the process of learning how to live with it and how to adjust to their new bodies and the way they experience themselves in the world. Maryam’s attitude towards her yoga classes illustrates this: “I can’t do what others do and I do it my own way but they don’t mind, but it makes a difference and I like it.” She was able to acknowledge her limitations and own her difference. From that point, she has been able to accept herself for who she is and give herself what she needs.

By beginning to negotiate with acceptance and relate differently to their pain, the participants have been able to connect with their sense of agency and responsibility. By drawing upon their resilience, they have managed to shift their perspective when it comes to finding the best way to deal with their difficult circumstances, as illustrated in Toni's account:

> Basically, you just need to get on with life. Yeah, basically, I lost a lot of trust. But I feel like it had to happen because it just built me up a bit more, brought up my resilience a bit more (…) I feel like maybe I was reliant on them (clinicians) too much and maybe I don't need them as much as I think I needed them. I need myself and I need to know what I need to do for myself to help myself to stay well, as well as I can and as much as I can, instead of relying on someone else to do that for me.

Ruth is aware that she will not be pain-free again but there are certain things that she can do to keep pain at bay: "I think now, I've got to manage the pain by doing exercise, Pilates, you know, not walking too much perhaps, find the way to manage."

Something that most participants spoke about was the fact that they did not rely solely on traditional medicine to alleviate or even diagnose their symptoms; they did their own research and opened up to other disciplines that could also provide some form of help. Some participants sought help from complementary therapists such as homoeopaths, osteopaths and acupuncturists. They all reported that, although the impact on their pain and general well-being was not dramatic, they felt it was a form of support nonetheless. At the same time, they were appreciative of the time they were given to tell their full story and for someone to approach their illness in a holistic way, something different to what they had experienced so far. Jane expressed that she liked the consultation process with her osteopath because "it was really long and he asked me all these really detailed questions about my neck. So that was quite impressive".

Since there is no specific treatment for their conditions of chronic primary pain, the participants have engaged in active research and discussion with other patients to find different ways to help themselves and do what they can, as opposed to expecting others to heal them.

They have also taken responsibility for their mental health. Almost all of the participants have had, or are having, some form of psychological support, which has helped them to relate differently to their experience of pain. From a place of hopelessness and helplessness, some of them have been able to find some agency and have a more active role in their own well-being. For Ruth, this has been experienced in her capacity to feel more able to manage her symptoms, as opposed to fighting them; she can read her body better now and cater for what it needs, whether by learning how to pace herself or by doing more exercises.

Nataly felt that, with time, she has also been able to understand that her pain, although never absent, is at times possible to manage with more kindness and self-compassion: “I have learned over the years, okay, this hurts; I do my needle mat and I do my stretches and I put hot water bottles, I learned all that, try to do my meditation app, I’ve learned over the years.”

There is overall recognition and acceptance that pain is part of their lives. This only came, for most of them, after touching the depths of despair, hopelessness and helplessness. It is evident that this is not, and never will be, a linear process, since it requires constant negotiation and engagement, learning from themselves and others. When they stop fighting their pain, both physical and emotional, they are able to listen to their bodies and connect with their specific needs. The latter has been a difficult journey and their leaps to agency and responsibility have also required an enormous effort of self-compassion and self-kindness.

Subtheme 2. 4: Things happen for a reason: making meaning of the experience of pain

All of the women spoke about their attempts to make sense of their experience of chronic pain. It was possible to observe that, in all of the stories, there was an effort to link the suffering caused by pain to something bigger, something that would help them to understand the *why* or the purpose of their pain.

For Toni, there was an emotionally loaded process of self-enquiry regarding the causes of her pain and her responsibility at the onset of the illness. This assumes that everything happens for a reason; therefore, there should be a plausible explanation for the pain:

> I kept thinking, in the beginning, kept thinking, "What have I done so bad? Why have I got this, why is this happening to me?" I try being a good person, but you start questioning when you've got all these pains.

Since the experience of pain is connoted as negative, it is assumed that pain is the consequence of having done something wrong. Pain is, therefore, a punishment for wrongdoing even when the wrongdoing is hard to identify.

Maryam, on the other hand, attributed a different meaning to her experience of pain. In her case, her longstanding experience of emotional suffering, depression, trauma and PTSD could not escape the realm of the body. In her view, her pain was the expression of her emotional pain. This awareness made her approach her physical symptoms from a different perspective, acknowledging the need for help, from not only a medical standpoint but also a psychological one, wanting to heal not only her body but also her mind. She understood her experience of pain as both mentally and physically debilitating and was also aware of how her depression and pain influence each other.

Similarly, Elena felt that her physical symptoms – pain, in particular – were the result of difficult emotional experiences that she had from a young age. Early bereavement and difficult family relationships were represented through her body, through pain. She felt unable to let go of these experiences, which in a way she absorbed in her body. In her account, Elena explains how her different experiences of pain have been linked to specific situations in life that she has been through. She can trace in her body the intensity of both suffering and love: "A loving relationship, all the migraines that I developed, and the cramps, they came back when I started the relationship, which was very strange; I think it was emotional, all this loving and emotions you know."

However, as well as attributing different meanings to the origins of the chronic pain experience, some participants, such as Ruth, had been trying to find the symbolic meaning and purpose of their physical symptoms.

> And I've been thinking [about] what the universe is trying to tell me by having this problem (…) I've been trying to think, maybe the walking, because it's to do with the walking, suddenly I get stuck … so maybe I'm not being able to walk forward, like literally what is it that stops me from going forwards in my life? So I've been looking at this element and it's true you know, there is some emotional element probably within as well…

Feeling stuck in her body is, for Ruth, interpreted as the experience of feeling stuck in life. Her body is communicating something about her experience in the world and she is trying to make sense of this. As well as this interpretation, Ruth has dedicated some time, alone and in therapy, to exploring these physical manifestations of her body and has been trying to create a meaningful elaboration of them. Being in constant pain can feel very alienating for most people and Ruth has certainly been through this. However, she has also experienced the fact that pain brings death awareness, which she sees as an opportunity to evaluate life and explore new ways of living. Similarly, she feels that, despite the alienation that pain brings, she is not the only sufferer:

> Yes, it feels alienating [pain] but at the same time you realise, how many people got the same problem, so you can be closer to these people too, you can engage, you can realise that you are not the only one.

She was able to connect with a sense of something larger, a sense of belonging that makes her rethink her experience of pain as something that no longer creates distance but rather a feeling of being closer to others. Ruth found a sense of interrelatedness, connection and belonging where there used to be separateness and isolation.

Toni felt that, from all the suffering experienced, she was able to create something out of this and assign a new meaning to her experience. Realising that she was not the only one suffering, the only one who felt lost and isolated, she decided to create a new support group in her borough where she will be able, with other people, to provide specific advice and activities for those suffering from fibromyalgia.

> Yes, I'm excited for this support group; I feel like it's going to help people more and put us in a better state mentally and physically as well (…) I'm hoping that in the new group, we can scrap that whole thing and I feel like it will reach a lot of people, it will help a lot of people and that's a goal for me. I want to help people to be able to manage their pain (…) I think I can be useful to people.

Making sense of life events and the assumption that "everything happens for a reason" was also conveyed in Toni and Vanessa's accounts. It was possible to observe how they evaluated their lives and looked at their past from this standpoint, which helped them to make sense of, or validate, their decisions in life. Toni felt that becoming a mother at a very young age was, after all, the best decision, as she was fit and pain-free, a very different scenario compared to how she feels now. Her children still need her but she is aware that they are old enough to fend for themselves if needed.

In the same way, Vanessa spoke about a time in life when she felt free to live her life fully, to live her youth, and did not miss out on life. She treasured these moments, held on to them, because, for her, it made sense that she did everything she did before pain sucked the life out of her:

> You'd expect a 21-year-old would be going clubbing all the time, right? Well, I think everything happens for a reason. When I was younger, I used to drink a lot, and I see why I did that then, 'cause, imagine I didn't do that, experienced that. Imagine from a young age, I didn't get that experience, to see what it was like, to express myself in that way. Like everything happens for a reason and that's how I see it, why I did what I did in the past; because I don't have the strength to do it now. Does that make sense? Like it was always meant to happen. That's what it feels like.

The different accounts show how, one way or another, there is always the intention to make meaning, to understand the past, present and future from the place of not-knowing and not-controlling imposed by pain. The accounts showed that the women found their agency when telling their stories and making sense of their pain and the different life events they had been through so far.

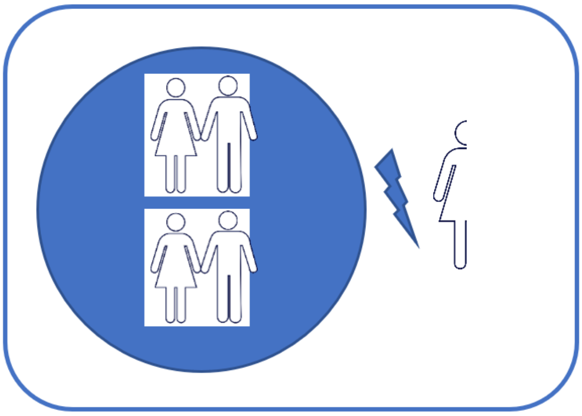
Theme 3 – “This is real”: the need to be legitimised

Theme 3 – "This is real": the need to be legitimised

Subtheme 1: Not been heard, not been seen

Subtheme 2: An uncertain aetiology, a questionable diagnosis and a bleak prognosis

Subtheme 3: To believe in the unseen



Overview

All of the accounts described an exhausting journey within the healthcare system that failed to provide them with enough opportunities, openness and the time needed to understand how pain affects their lives and the lives of those around them. Being able to convey what their unique experience of pain is for them needs time, openness and the intention to understand on the part of the other. Regrettably, this has been far from the participants' experience, since they have constantly been met with not only rushed appointments but also preconceptions about both them and their symptoms. At the same time, they felt that the lack of time provided gave them few opportunities to have a collaborative process when it came to their health management, which made them feel disempowered.

Their efforts to be understood came from their desperate need to know what was wrong with them. Receiving a diagnosis was seen as an act that would not only provide effective treatment but also legitimise their suffering. Unfortunately, these efforts were only rewarded with diagnoses that can be contested, misunderstood or simply dismissed.

It is possible to say that the lack of visible signs of pain, as well as the lack of information on women's health and pain, made them feel that their pain and their illnesses were not taken seriously, and in many cases they were normalised. This made them feel dismissed and disbelieved most of the time, not only by health professionals but also by everyone around them. When their experience is not legitimised, it is not seen and therefore not treated as real.

Subtheme 3.1: Not been heard, not been seen

Most women spoke with disappointment about their encounters with GPs and healthcare professionals in secondary care. One of the main aspects evidenced in the interviews was the lack of time provided for their consultations when seeking help for their pain. Most of them felt that they had to rush and summarise the list of symptoms that they were experiencing without being able to expand on their daily struggles and the suffering caused by pain.

Before being diagnosed with fibromyalgia, Toni experienced different digestive problems, so visits to the GP were frequent. She felt self-conscious about this and worried about being perceived as a malingerer:

> I would like them … you know, when you walk into the room, sometimes you can tell when the doctor

> is going to be okay or not okay with you. There's an atmosphere, it's kind of you get that feeling of, "Oh, it's her again" or something like that. I would like them to not have a preconception before I walk into the room, so they will say, "This is going to be like this or like that".

The preconceptions and assumptions held by clinicians regarding women who present with pain were perceived as an obstacle to the women's access to care. There is, according to most of the women, a fundamental lack of willingness from GPs and other health professionals to remain open and curious and to offer active listening when it comes to their experience of pain. During consultations that at times lasted under ten minutes, they rarely felt heard and understood, feeling instead dismissed and not taken seriously.

Jane and Elena also felt that clinicians held preconceived ideas, which prevented them from providing the active listening needed to understand their symptoms. They would expect the consultation to be more of a conversation about their experience of pain and how pain affects their lives in different ways. Regrettably, they are often met with passive listening that makes them feel dismissed and lose trust in the healthcare system.

> (Jane) And the questions … nobody seems to be asking me questions as such. They don't really ask me. They look through my diary and they go, "Hmmm, okay, is not working, so we will put you on this treatment or medication and we will see you in six months". They are not really asking much about me, how I've been.
>
> (Elena) People and doctors don't understand also what you need to do in your daily routine, in your life. You don't have someone who can come and cook for you or someone who can do the shopping for you so you still have to do ordinary things that everybody has to do. And the doctors tell you, "Don't push". But if you don't push, what do you do then?

Toni shared the same experience about her medical encounters: she did not feel seen or heard. She expressed how much she would like her GP to stop typing on the computer and make eye contact while she talks to him so he can see her, see her pain and see that she is suffering.

And, for most of them, this lack of listening is caused by the lack of time they are given to tell their story. They are aware that what they need is almost unachievable within the NHS and this is why some participants like Dorothy considered private healthcare as an alternative; they were, after all, paying for the time to be heard:

> I went to the (private) pain doctor and I felt such a relief that he was actually listening to me; he was taking me seriously and felt that I was going to get somewhere with him (…) He was actually listening to every word that I was saying (…) Yes, I felt like I was being heard. I felt like he was suggesting a treatment plan, he was just taking me seriously.

Similarly, Jane, Ruth and Elena found that by seeing complementary health professionals, they were given the time and attention that they needed. Jane spoke about the positive encounter she had with her osteopath and how she valued not only the time she was given but also the questions that she was asked, which revealed the osteopath's genuine interest in her condition. Elena had a similar experience with her homoeopath. She felt understood because he took the time to get to know her, to learn about not only her pain but also her life.

Vanessa felt that, when primary healthcare professionals find themselves unable to offer the time their chronic pain patients need, they resort to a counselling referral as an opportunity for the pain-bearer to have space and time to talk about their pain. However, this does not meet Vanessa's immediate needs: "They are like, "Oh, you need talking therapies". No, it's not about talking therapies. "We need to talk about this here because it is about my pain".

Patients need to be listened to by their GPs and specialists; they need to hear and feel that they matter, that their pain is real and that it is bad. They need doctors to be open, interested and willing to do their best to help them. For most of the women in this study, this was far from the case.

By failing to see pain as a lived experience rather than a circumscribed physical phenomenon, the clinicians were perceived by the participants to have a reductionist approach to pain. This is manifested not only in what has been described above but also in the way they treat and approach complex chronic pain.

Ruth and Toni described how they feel that the NHS sees patients not as a whole but as parts.

This was demonstrated in their experiences of going to the GP with multiple symptomatologies and finding resistance on the clinician's part to focus beyond one symptom, one part of the body. Toni stated:

> It was like they were not looking at everything as a collective, they were looking at, "Okay this is a headache, I'm going to give you this tablet" … you know what I mean. They weren't looking at the whole picture.

This resonates with Ruth's views on the pain charts that clinicians use to assess pain, which in her view fail to address the fact that some types of pain are slippery and ephemeral, impossible to capture and understand from a specific point in time:

> And often when you go and see the doctor, they try to say…. they give you a chart. I think these charts really irritate me, it doesn't really, doesn't say much about how you, how you …, maybe right at that second but maybe 10 minutes later, you could write a totally different chart, so it doesn't really.

Similarly, Toni spoke about how her fibromyalgia was only diagnosed six years after the onset of symptoms, attributing this delay to the fact that her symptoms were addressed in their singularity as opposed to seeing the whole picture. To Toni's surprise, when the rheumatologist finally diagnosed her, he did not communicate this directly to Toni, so she only found out she had this condition when visiting her GP with another pain, which made her feel disempowered and dismissed.

> So yes, I went to the doctor (GP) with another pain and they said that, "Well, it's common in fibromyalgia to have these, like nothing happens, there's no damage or anything". But that was the first time I heard of it. And I just thought, okay, "Was that the diagnosis?" 'Cause obviously, the rheumatologist wrote to them, but he didn't tell me personally.

Other participants also felt disempowered and uninformed when it came to their knowledge about their medical conditions. Jane had a similar experience when having her migraine assessed by her neurologist. Jane had a theory that her pain could be related to potential neck arthritis; since the condition ran in the family, it was not a far-fetched hypothesis. However, the consultant was reluctant to explore this further and quickly dismissed her opinion on the matter.

Had the consultant explored this idea and gone over Jane's medical records in detail, she would have been more inclined to consider her patient's theory:

> And it's funny, 'cause I was applying for the disability benefit, the PIP, and I asked for evidence from the GP, so they gave me a whole stack of everything and I was going through it and there was something there from, maybe from 10 years ago, and it said something there of me having arthritis! And I was like … Mum! I showed her and we were looking a bit confused because no one has ever told me that I have arthritis in my neck. So, I was confused. I was looking at it and thinking, that's something they never discussed or said they thought I had.

Through Toni's and Jane's accounts, it is possible to say that, on some occasions, clinicians fail to establish a supportive relationship and communication so that their patients feel able to discuss their diagnosis, what it means and how it will impact their lives. In the same manner, by not establishing collaborative communication, clinicians might miss the opportunity to hear the patients' perspectives, their needs and their knowledge about their bodies and their lived experiences.

Another aspect that made participants like Toni and Vanessa feel completely disempowered and not heard had to do with their doctors' decisions about their medication. Both felt that the medication prescribed to them was not helping to ease their pain and they still felt unable to carry on a normal life. Whenever they talked about this with their GPs, they were met with disbelief and suspicion, their plea misjudged as drug-seeking behaviour, as was the case for Vanessa:

> They treat you like an addict, just because the drugs can be addictive. When you are suffering from a long-term condition anyway, you are going to need it long term, whether it is addictive or not. I am conscious that people get addicted to it but they need to look at people like actual individuals, not like everyone else…

All Toni wanted was for the clinicians to understand what, for her, was very clear:

> Literally, I would love it if they actually sat and listened and not like having a preconception in their minds or saying, "You are going to get addicted to this tablet so I won't give it to you" or, "I won't

> change your antidepressant ‘cause I don’t want to have to review”. Because they said that if I was to take a different tablet, like if I have Tramadol, I can’t take it with the antidepressant. The thing is that if I’m not in so much pain every day, I wouldn’t feel so depressed, I wouldn’t feel so anxious to go out.

The need to be heard and understood by others was evidenced during the interviews when the participants expressed their gratitude for the time they were given to talk about their pain and, most importantly, how pain has impacted their lives. Vanessa stated:

> I’ve never really gone into depth; it is in my head but I haven’t done it physically speaking. But it’s nice to have somebody who actually listens to you (…) I felt like, I felt like you understood more than a doctor (…) You listened to how bad my pain gets and you’ve been quite sympathetic. (…) It’s nice to be able to express myself. I feel like doctors do judge as well. I feel like the difference between you and a doctor is that doctors judge, you don’t, you understand and they don’t.

The pain experienced by the participants is, like most chronic pain, complex, which can only be grasped in the narratives and stories that women so desperately want to tell but are hardly given the time to do so.

When patients are not given the time to tell their story, a story that captures the full extent of their illness, and when they are met with preconceived assumptions, they feel disempowered and frustrated. They keep asking themselves how it is possible for clinicians to arrive at a conclusion when they have barely listened to them and what their bodies need to express through language and stories.

Subtheme 3.2: An uncertain aetiology, a questionable diagnosis and a bleak prognosis

It was observed in all of the accounts that receiving a diagnosis was a slow and frustrating journey. This process was dominated by anxiety and constant worry about different kinds of pain, often of an uncertain nature. The women knew that there was something wrong with their bodies; however, they felt powerless to identify the cause or the diagnosis of their illness.

Diagnosing their conditions was not within their remit and they had to rely on the clinician's expertise (and up-to-date science) to provide the answers they were so desperately seeking. In most cases, the test results were normal and there was a lack of physical evidence or injury that could explain their pain. It was hard to make sense of a pain that was felt both so acutely and constantly while being told by their clinicians that there was nothing physically wrong. For Toni, getting normal test results was in a way disappointing; on the one hand, her life had been completely impinged by pain but, on the other, there was no medical evidence to prove there was something wrong with her body. Without a diagnosis that could explain her symptoms, she would continue to be told that everything was normal and everything was fine when, in reality, her experience was completely the opposite.

> I feel like because obviously if I go for a blood test and they've got their markers and if you are off the markers they tell you, "You've got this". But with fibromyalgia, obviously, everything seems to come back normal. So, to the doctors, 'cause they see one second of your life in your blood they don't take it seriously.

In some accounts the participants expressed how they felt their pain was being normalised and therefore they had no choice but to accept their fate. This was evidenced in Dorothy's case when her excruciating menstrual pain was treated as normal with over-the-counter painkillers. It took more than two years for the doctors to decide to carry out some tests, and during this time she had to suffer the pain and anxiety of knowing that there was something wrong and that her pain was far from normal.

> I knew there was something wrong, but I felt very frustrated going to the GP and they wouldn't listen to me because to book an appointment it takes quite a while to see a doctor, and for them to dismiss you like that, over and over again, just repeat the same tablets but they have no effect. It was very upsetting and frustrating and I felt frustrated with the system.

The latter was also evidenced in Ruth's account, who, after many years of debilitating pain, was finally told that she has osteoarthritis and that her pain is degenerative. In a way, her pain was normalised, even when her pain meant being bedbound for months: “Yes, that is normal … Every time you go somewhere, the doctors, my GP certainly doesn’t seem to be concerned and thinks that is degenerative, there’s not much you can do ... take some painkillers.”

When facing the lack of medical evidence to explain her pain, Nataly felt that she was perhaps imagining her symptoms, which, as many people say about her condition, were all in her head.

> There were moments when you think that … you feel a bit like a hypochondriac (…) Now I know that it wasn’t in my head. I did because it was a good three years and I thought, “Okay, maybe it is in my head”. Maybe I am … but it hurts!

The need to have a diagnosis is motivated by the assumption that, by knowing what the illness is, there will be specific knowledge about the treatment and cure. If the clinicians are unable to decipher the puzzle of their symptoms, they will also be unable to provide the best course of action to tackle their pain.

After seeing different consultants and having several examinations and tests because of suspected endometriosis, Dorothy was finally told that she did not have the condition, which landed with a mixture of relief and frustration:

> You feel like, it’s good that I don’t have endometriosis, I read a lot on the support groups and it seems quite bad. But then frustrated because, you are still not fine, there is still something wrong with you, that you don’t know what it is.

For Dorothy, it was the lack of knowledge and training about women’s health that made clinicians normalise her period pains for years, which delayed an appropriate diagnosis and made her feel frustrated and dismissed: “Because doctors are men, they don’t understand. They don’t know what [it] is like to have a normal period (…) And yes, it used to make me very angry, very frustrated but people like that need to be educated.”

Elena also felt that, when it comes to women’s health, sometimes the medical gaze fails to take into account the complexity of women’s bodies and how hormones can impact their bodies during menopause, which makes it hard to understand what is causing what and also what it means to be a woman and the responsibilities associated with this gendered role.

> I have to talk to myself and this is what annoys me and I'm thinking, "Is this also your menopause adding to your problems?" I think it's a combination with the hormonal, for women hormones … a lot of emotions that women take more on 'cause we are mothers also, and there are more women in this world with children on their own than fathers.

When Maryam received her diagnosis of fibromyalgia, she felt relieved that her illness had finally been named, giving it a dimension of reality and having a sense of what was needed to manage her condition. For Elena, receiving the diagnosis was legitimising and validating; it made her feel less alienated from her experience and hence from the world, and she found a new sense of belonging:

> Now I think I am less confused because I met a lot of people with the same condition. I went to a support group; I joined a support group for people with fibromyalgia, in the hospital and outside. And you feel like you've got a little … it's awful to say this, but you've got a stamp to say, "I've got this and I've got this and it's okay, can you please help me?"

However, the relief of having a diagnosis of fibromyalgia was short-lived since the women later realised that the condition is poorly understood by both the medical profession and the general public. And although it is treated as a real illness, the fact that the causes are not known makes it very hard to treat and perhaps also the reason why patients need to see so many specialists before getting a diagnosis. Nataly expressed that "they don't know exactly how to treat it so you become a test bunny with the medication".

And Elena:

> Well, doctors, because now even my ordinary doctor is gone, so I see different people, so I have to repeat myself and nobody knows about fibromyalgia (…) Doctors, they don't know. Some do because they are interested themselves in finding out.

For Toni, receiving a diagnosis of fibromyalgia helped her to make sense of her symptoms and to understand that the different problems she was experiencing were due to the same condition. However, she felt that once she was diagnosed with fibromyalgia, clinicians began to assume that all her physical symptoms were related to the illness, dismissing her concerns.

Maryam felt that receiving a diagnosis of primary chronic pain meant she was no longer treated by clinicians with the same urgency and compassion that they treat other illnesses such as cancer. Although their lives are not under immediate physical threat, all of the participants felt that chronic pain insidiously erodes their lives, and the lives of those around them, having devastating consequences for their mental and physical well-being. But, despite this, some of them felt written off, as described by Maryam:

> Not good, you don't feel good, you feel that you've been abandoned and that your pain has not been taken seriously by scientists, even fibromyalgia, it's only 20 years that they have had this diagnosis. Previously, all the doctors were saying to the patients, "It's in your head, you are making it up!"

For participants like Dorothy, it has been a tough journey having to accept that her pain is not necessarily associated with tissue damage and that her pain is unlikely to be cured and that pain management is the best and single outcome:

> The pain doctor said, in pain medicine, there's no answer, you have to try all sorts of treatment to find something that is manageable 'cause all they care about is managing the symptoms and not thinking what's wrong with me.

And Vanessa:

> It's hard to find somebody that understands your pain; no matter what the cause is, it is still pain. Sometimes I would have liked that I had never been diagnosed with it; sometimes I wish it was worse so that someone would take notice.

Most participants expressed their gratitude during the interview for the fact that research is being done on the topic of women's health and chronic pain. They felt this was an area that had been overlooked by science and would like to see more done, not only because of the potential impact of this for their well-being but also because it will create more general awareness about conditions such as fibromyalgia. Maryam expressed her hope: "Yes … you know, hopefully, people like you, scientists, research like this, I hope that things can change for the better."

And Dorothy:

> I think that what you are doing is great, is a step in the right direction and with that, more people and more research on pain, the physical aspects or the mental aspects of it. I think it's needed, it's a long time coming.

And Nataly:

> I'm just really glad that you are doing this and I hope that there will be more for people in the future and I hope that people would be more understanding just because someone doesn't look ill … people judge very quickly and I think they should be a little bit less judgemental.

Across all the accounts, the participants reported that, although having a – very much sought after – diagnosis of chronic pain was validating and legitimising, it was not entirely reassuring and helpful. Although a specific diagnosis was given to most of them, which they can use to communicate to others about their experience of pain, the aetiology remains unknown and, most importantly, very difficult to evidence.

One of the biggest challenges that the participants articulated is having to accept that their pain is no longer a symptom but a chronic disease.

Subtheme 3.3: To believe in the unseen

According to the findings, the experience of living with primary chronic pain presents a double challenge. In the first place, the fact that pain is both a sensory and emotional experience makes it difficult to translate into words and objective reality. The participants felt that, through language, they were not able to convey how much, and where, they hurt, as stated by Vanessa and Dorothy:

> (Vanessa) No words are ever enough to describe my pain; it doesn't seem enough for what I feel; no matter how much I describe the pain, it feels like it's more. I could never describe it enough. I don't think there's any word out there that could describe how awful it is. I don't think there's a word to describe how intense it is and how overwhelming it is, I don't know how to describe it any more.
>
> (Dorothy) but you don't know what is like unless you are in this situation. No matter how much you

> explain, it’s just like constant pain or like they are cutting a part of you, constantly, stabbing pain. It’s hard to understand unless you are experiencing it.

Second, as well as having to deal with the barriers imposed by the nature of pain, when it comes to communicating about the experience, the participants also felt that their specific conditions of chronic primary pain made it even harder for them to feel understood. The fact that their pain is not necessarily associated with tissue damage or perceived injury – as it would be in a broken bone or an acute pain caused by a medically evidenced pathology – makes it even more difficult to be understood by others. Vanessa says: “Yes, it’s not like I’ve broken a leg. Is not like you actually broke something and they can see it on the X-ray. It’s the way they perceive it I suppose.”

For almost all of the participants, the invisibility of their pain in the eyes of others, and how their disability may be questioned, is one of the most challenging aspects of their lived experience. This was the case for Toni:

> People look and they don’t see anything wrong with you. They have some expectations of you but you can’t fulfil that cause you are in a lot of pain and you can’t do what they want you to do or walk as fast as they want you to walk or park like you are supposed to … it’s like, it feels like, it makes me feel invisible as a person ‘cause people don’t treat me how I need to be treated in that sense.

The extent to which people in pain can become visible, acknowledged and supported depends on the pain-bearer’s ability to convince others that they are suffering. Some participants mentioned that if they were in a wheelchair or using crutches, people would be more likely to empathise with their pain, which would now be visible through these objects that people would associate with a disability. As Elena mentioned: “I’ll have this seat that I can carry and I can sit down. Because people see, when people see something, they understand it.” Similarly, Maryam commented: “And I’m thinking, OMG, if I were disabled, if I had crutches in my hands… Yes, they would understand me, but because they can’t see that. They make a judgement immediately, “She’s mad.”

The problems of the invisibility of pain were expressed by Toni in the following:

> Yes, it’s like, you can sit in the priority seating but because you don’t look ill, people think, “Why are you sitting here” kind of thing, but I have the right to sit there. But I feel people judge me if I don’t have my walker or crutches or something.

But even when such objects do exist, such as the PLEASE OFFER ME A SEAT badge provided by Transport for London, for people who may struggle to stand for too long, pain-bearers are likely to be ignored by fellow passengers, as happened to Dorothy:

> And there’s been times that I have been on the train and I have the badge on for the seat and even sometimes people won’t offer you the seat, so I was sitting on the floor, and even sometimes when you are on the floor people still won’t offer you the seat.

In the same line of thinking, almost all of the participants spoke at length about their frustrations when people assume that, because they look good externally, they should be feeling well. Elena felt that often, when people tell her that she looks good, they are in a way dismissing her condition, feeling that they only say it to make her feel good. It is not about not engaging with the compliment but about the assumption that looking good externally is always an irrefutable sign of good health:

> I look good for my age, the doctor told me three times I look good. The counsellor … I went to see the counsellor last week, she said, sorry for the third time, “You look so good”. I said, “Oh, thank you, what shall I do with my looking good? What can I do?”

Some participants expressed their upset, not only at the fact that their illness is invisible but also because their efforts to cope with everyday pain and other symptoms may have a detrimental impact on the way that people perceive their illness, as described by Maryam:

> Even when I go to DWP (Department of Work and Pensions), and all the guys they look at me and they think, you look okay, why don’t you do your job? And I have to keep telling them that my central nervous system has broken down.

This creates a paradox in the sense that, in order to feel believed and validated, they need to look unwell, their pain needs to have a visible element, and they need to look ill. Therefore, any attempts to look after their appearance or make an effort to feel better about the way they feel about themselves will only do them a disservice.

The participants reported that, at times, they did feel more understood and validated by others, especially when those were pain-bearers like them. Most participants had joined support groups where they were able to interact with people with similar conditions. For Jane, this made her feel less alone:

> Maybe some things that I may have said, when I described my pain on a particular day, sometimes they said, “I felt the same” or they’d say, “Yes, I feel exactly like that!”. Sometimes I read things on the Facebook pain group chat, a forum. And I’m like, “Yes, I feel just like that”.

But although these groups, whether face-to-face or online, have been a source of support and understanding, participants like Vanessa, Toni and Nataly felt that they could be detrimental in the sense that they could create more distress and anxiety. At times, members of these groups have been judgemental, which may lead to feelings of inadequacy and isolation. At other times, participants like Nataly felt that attending these groups where people continuously spoke about their despair was not necessarily helping their well-being:

> And I stopped doing the group because it had a negative influence on me, cause I’m like a sponge, I stopped even Facebook, I stopped looking at some groups because it would upset me, I stopped watching certain things…

Being understood is not necessarily what the participants needed the most. To their knowledge, pain is, and always will be, an experience that escapes language. What they need, according to the analysis of the findings, is to feel validated and believed, that what they suffer is real and debilitating. Empathy is needed for this to happen, and, for participants like Maryam, real empathy can only be translated into action.

> It’s through the actions, through the words. If somebody is saying, “Okay, Maryam, I know how you feel, come to work at 10 or 11 in the morning, fine, take your work home, do it at your own pace, if you feel ill on Friday, do it Saturday if you want it”, so you can see that there is an element of

> comprehension.

At other times, it is subtle changes that made them feel acknowledged – recognising that others are able to enter their reality and adjust to their pace, their way of being-in-the-world.

As Ruth stated:

> If I need to sit down sometimes, or if I'm walking with them, they will slow down, they won't mind or make a big deal, they would just make it part of the trip, of the journey, you know, they just take my pain as sort of part of me somehow and we go along with it and they don't make a fuss out of it.

It is hard to live a life ridden with pain. But at times, as has been evidenced in the accounts, it is harder when their pain cannot feel legitimised or believed. When others fail to acknowledge that people with chronic pain have an invisible disability, they may also fail to respond from a place of empathy, kindness and compassion. The consequences of not receiving something so fundamental are both hurtful and harmful.

Reflective relational encounter

This analysis would not be complete, and would fail to address intersubjectivity entirely, if it did not account for the phenomena of the encounter with the participants and their narratives and how these encounters became layered with intersubjective meanings.

In an encounter that remained both present and open, a connection was established and new knowledge emerged, and their pain left the private sphere, to become ours; it let itself be seen and understood, and the invisible became visible. The pain was communicated via something other than language; precisely in that intersubjective space, something emerged, like the space between an embrace.

On many occasions the pain was described as an antagonist, a threatening force. The image of an invisible attacker kept bringing to my mind the plot of the *Invisible Man*. In the film a woman is haunted by her abusive ex-husband, who has, through sci-fi technology, managed to make himself invisible. The terrorising and threatening presence does not seem to be the most upsetting thing; it is the invisible man's capacity to play with the protagonist's mind, the invisible gaslighting, that makes it even more distressing to watch. Interestingly, this made me reflect on the fact that pain is not the only non-visible phenomenon that women have to deal with in our society.

There was a realisation that, if you allow it, the pain will be seen and felt by the witness. And now that I know that this is indeed possible, I cannot help but wonder: What do we do with pain? How do we hold suffering? How do we contain sorrow? How as researchers can we sit with the ethical demands of pain? With each participant and their expressions of gratitude, not just for listening but also for conducting a study on their under-researched conditions, I was left with a big sense of responsibility, of not doing enough and wanting to do much more. I reflected that perhaps this is how healthcare professionals must feel at (or most) times, their hands tied, powerless. I could understand why in our society pain is better silenced, subjective and ineffable. It seems more convenient to believe that it is not us turning a blind eye but rather pain's inaccessibility and quintessential private nature.

I remained conscious that I was offering something that felt so alien to the women's experience. So much time was given to their pain! They were eager to share the narratives that they had been desperately trying to convey to others, what it actually means to live with chronic pain. I was humbled by their openness and their willingness to show their vulnerability and sad to realise that vulnerability was, after all, inescapable. I was also aware of my role as a researcher, mindful of not getting confused between my psychotherapist's role and that of a fellow woman aware of gender injustice. I used my therapeutic skills with care and responsibility to enter their world, and my phenomenological learnings to put mine aside.

I kept a mindful stance regarding my possible views and feelings regarding gender inequality, especially when it came to health, becoming aware of my emotional responses and putting them aside to allow the participants to own their narratives, as opposed to imposing mine. I would not push the subject of gender when not appropriate and would not direct the conversation towards my own assumptions.

Similarly, I trod very carefully regarding possible assumptions about the links between trauma and chronic pain. Aware that this might be a common association in psychology (Banyard et al., 2008), I did not want to impose these assumptions and did not let them guide my enquiry unless it was brought up by the participants. When these connections were made, I kept an open and respectful stance, acknowledging and letting the participant decide the depths of exploration. My background in psychology and psychotherapy has undoubtedly shaped my horizons of interpretation. Therefore, I had to place special awareness on the tension between the bracketing pre-existing assumptions and psychological hypotheses and stay present, open and, most of all, curious.

In the following chapter I will discuss the findings and how they relate to the theoretical and empirical literature, as well as the research question of this study.

CHAPTER 5: DISCUSSION

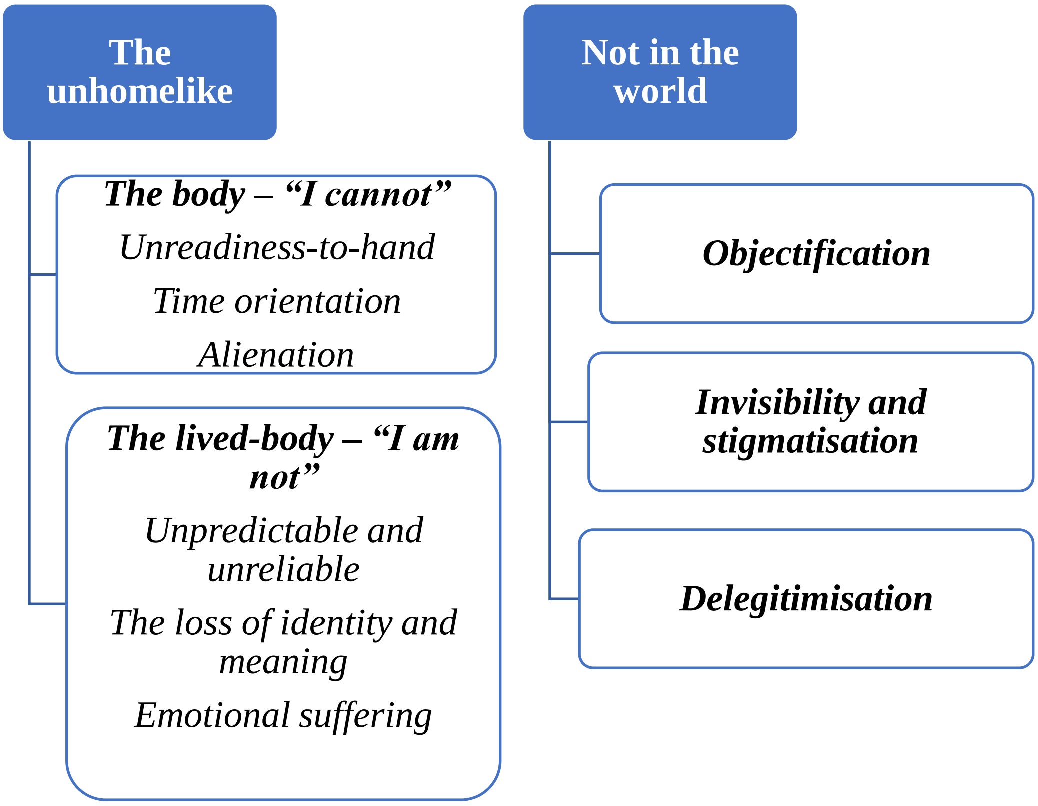
> *When you stand in the place of pain, you are no-one. There is a poignant line from Virgil's Aeneid describing one of the heroes found dead in anonymous circumstances: "corpe sine nomine" i.e., a body without a name. Belonging is shredded. You are visited and claimed by a nothingness which has neither contour nor texture. Suffering is the harrowing and acidic force of anonymity. You are utterly unhoused. Now you know where Nowhere is. No one can reach you. (...). It almost wipes your signature as an individual and reduces you to faceless clay.* (John O'Donohue)

Introduction

The purpose of this chapter is to discuss the themes identified in the findings within a phenomenological tradition, which means a discussion that understands experience as lived-experience within the intersubjective lifeworld. Hence, the intention is to discuss pain not as a subjective and insular experience but as something that is shared and situated, that speaks of connection and separation at the same time. These findings will also be evaluated within the theory and literature presented in this study, with the aim of offering a new understanding or insight into the intersubjective experience of chronic primary pain in women.

Following the discussion of the themes, I offer a critical evaluation of this study by evaluating its limitations, especially those concerned with the methodology and the exclusion of other structures of power in the analysis. Recommendations for further research are also mentioned. And, finally, this study concludes with the potential implications of my findings for the field of chronic pain and how they may assist healthcare professionals involved in pain care, as well as researchers in the field of chronic pain, who may find the phenomenological findings a possible avenue for further investigation. Similarly, I will also mention the potential relevance of these findings in the fields of counselling, psychology and psychotherapy.

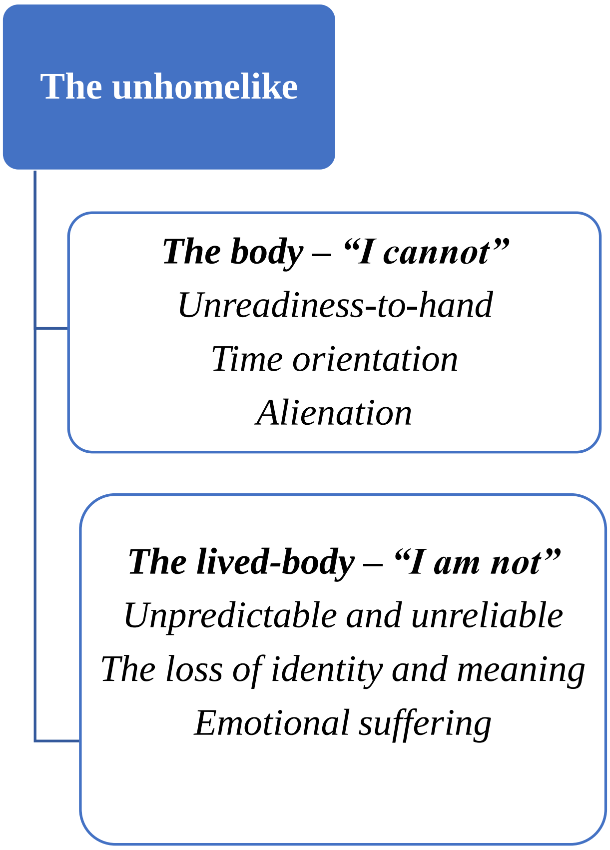
Discussion of the main themes



I have divided this discussion section into two main parts to disseminate and consider in detail the most salient aspects of the findings. The first part, **"the unhomelike",** is composed of the dimensions of the body and the lived-body, a purposeful phenomenological distinction to illustrate the alienation between the body and the embodied self. These dimensions describe the way that pain affects how the world is inhabited or, more precisely, the unhomelike way of being-in-the-world. The embodied self is impaired by the debilitating nature of chronic pain, and a gulf is created between the subject and the world, the latter unapproachable and as if moving away from experience.

The second part of the discussion, "**not in the world",** is concerned with the making and unmaking of chronic pain in the lifeworld. Women's chronic pain is a situated experience within a specific relational and socio-historical context. The subjective experience of pain unfolds in the lifeworld, which is inherently intersubjective (Geniusas, 2020). By the processes of objectification, delegitimisation and invisibility, the reality of their experience is questioned, thus not finding a place in the world that it inhabits. A disruption in their relationship with the world was unequivocally evidenced in the accounts, where the participants felt alienated, unacknowledged and isolated. The result is a general experience of being *not in the world* and the profound and isolating feeling of not belonging, which makes them endure the extra pain of separation.

The unhomelike



As will be illustrated in the first part of this discussion, two forms of separation or alienation were evidenced in the findings, an alienation from the world that the pain-bearer inhabits and the alienation between the self and her body. This is similarly described in Svenaeus (2015): "Pain does not only alienate us from our own bodies; however, it also alienates us from the world we live in by making it an unhomelike place to be" (p. 121). The body becomes an alien object, unable to respond to intentionality, giving way to a representation of experience or knowledge about oneself that can no longer find its place in the world.

As previously stated, a distinction between the dimensions of the body and the self has been made in order to illustrate the idea of separation or disruption of the embodied self. There is also a phenomenological distinction between the body, felt as an object, and the lived-body, immersed in the lifeworld of being and meaning.

i. The body – "I cannot"

First, I have identified the dimension of the body that, for this analysis, may resemble the phenomenological concept of *Körper,* the operational, objective and intentional body that, in the experience of pain, relates differently within space and time. Objectified as an alienating entity, pain captures the body, giving it its alienating properties. The impact of pain in this dimension results in the experience of the *"I cannot"*: an arrested body unable to engage with a world where time and space no longer make sense. As well as experiencing a world that becomes inhospitable, the women of this study also documented how they struggle to inhabit a body that no longer belongs to them.

Interestingly, this description of "the body" as an object reflects, to a certain extent, the way that it appeared during the conversation with the participants. At times, we were talking about them, their lived experience, but at others, we were talking about a differentiated entity, the third being in the room, their body in pain. The body was the theme, the pain the tinnitus of the body.

Unreadiness-to-hand

As Garro (1992) states, pain is felt as an ontological assault that challenges the relationship between the self and the body. In this sense, chronic pain transforms the experience of the "lived-body", where self and body are unified into an experience of an "object-body". The body represents a constraint in the relationship with space, and pain is experienced as an authority.

According to Merleau-Ponty (1945/2002), we are bodily engaged with the world and therefore "consciousness in the first place is not a matter of 'I think that' but of 'I can'" (p. 159). This means that bodily knowledge and sensorial experience of the world are a precondition for conscious and intellectual knowledge thereof. According to the findings, it is possible to say that the participants' engagement with the world was not from the place of the "I can"; on the contrary, their whole relationship with the spatial world was dominated by the "I cannot". The women, as also evidenced in Juuso et al. (2011), felt that they were being "constrained by an unfamiliar body" (p. 3), where daily chores and activities had to be carefully done and planned, and their bodies slowed down and struggled to catch up with their intentionality. The women had to cautiously consider doing daily chores such as cooking, walking and tidying up. They planned and wanted to do things but described how they had to wait for their bodies to catch up with their ideas.

As described in the Findings chapter, pain presents like an assault on the self; the body is no longer an instrument of will or subservience but a wall between the person and the world. This impediment to relate to the spatial world through an obstructed body can be connected with Heidegger's (1927/2010) idea of "readiness-to-hand" and how the body in pain becomes "unready", no longer serving the will. The equipment, in this case the body, an entity of intentionality and purpose, becomes unusable, obstructed by pain. As the findings show, the body in pain becomes unable to perform daily tasks such as taking a shower, cleaning, cooking, working and caring for others, to name a few. It is an obstructed body, no longer able to achieve its purpose. The "unreadiness-to-hand" of the body is evidenced in the blockage of movement, jammed joints, cramped muscles and, in the most extreme case, a bedbound, languished and fatigued body. Before malfunctioning, the healthy body, which was once fully functional and mobile, was also invisible, unacknowledged in the familiarity of its functioning or, as Sveneaeus (2015) describes, silently performing in the background. When in pain, the body becomes visible and a blockage of the actualisation of intentionality.

What in the past used to be done in an automatic and pre-conscious way, such as walking, taking public transport, driving or preparing a meal, becomes a very conscious and complicated action. Movements need to be measured and carefully planned, the anticipation of actions evaluated and a choice has to be made about how to conduct the body, which is no longer taken for granted. Even attending the interview for this study had to be carefully discussed and planned and precautions were taken bearing in mind their physical limitations.

It seems relevant to highlight the disabling aspect of chronic pain and, as such, it is possible to say that the relationship between body and space, and the relationship with others through space, is seriously compromised. The body is never isolated; it is always engaged in intercorporeality and, as such, never lacking in meaning. The body is always a body that others respond to in a fashioned way (Weiss, 1999). The body in pain is always a mother's body, a daughter's body, a carer's body, a series of specific corporeal exchanges with others (such as holding, hugging, texting) that are now affected by the disability.

Time orientation

The unreadiness-to-hand is also evidenced in the findings when participants talk about the slowness of their bodies; from this perspective, it is not just the spatial blockage of their bodies but also the tempo at which their bodies move, again another reminder of a faulty body. Aware of their slowness and obstructed bodies, their relationship with time is charged with frustration, their inner temporality not matching the objective time, what is expected from a healthy body. Scarry (1985) states that pain has the capacity to occupy not only the entire body but also what is beyond the body; like a tornado, pain destroys everything in its path, pain becomes totality or, what the author calls, "the single broad and omnipresent fact of existence" (p. 55). The pain, therefore, becomes the only certainty and the constant companion, never absent, only quiet, like a dormant volcano, a metaphor used by one of the women of this study.

Drawing upon the idea of omnipresence, as illustrated in my findings, pain isolates the sufferer within the realms of ongoing and never-ending presence, where past and future are almost impossible to bring to mind. As Morris (2010) states, "pain obliterates ordinary time" (p. 55). The omnipresent quality of pain presents as an obstacle in the exercise of imagination, memory and anticipation. Projecting into a future where there is perhaps the possibility of being pain-free is unrealistic; the unpredictability of pain taints the world of possibilities and dreams into a fruitless exercise. Travelling, studying and becoming a mother were, most of the time for the women, frozen prospects. Moreover, the time of biographical existence that was not ridden by pain felt disconnected and almost alien, a story that belonged to someone else. Similarly, chronic pain has felt so long-lasting that it is challenging to think of a past where pain did not force itself upon the women and their lives.

These findings support Geniusas' (2020) analysis of temporality and chronic pain:

> To suffer from pain is to be stranded in the field of presence, which, at the level of explicit temporality, is lived as infinite sameness in that it is cut adrift from other temporal fields. Such, indeed, is the way that those who suffer from pain (and especially chronic pain) qualify their experience. (p. 111)

Similarly, the participants in this research spoke about a new way of inhabiting time since their bodies are now slower and stiffer than before; tasks take longer and their tempo is different. They talked about the need to adapt to these changes, a task that was most frustrating and isolating, since it brought the realisation that this new rhythm and relationship with time, in a way, marks a disruption with the world and their engagement with it.

Temporality does not take place in a void and is not an isolated and individual experience because, as Merleau-Ponty (1945/2002) indicates, the subject inhabits time and, as such, is a time that is in the world, a lived-time that is also intersubjective. The participants did not feel slow; they felt slower and they were aware of dragging behind someone or something, a slow detachment from the world. In Wehrle's (2020) words, what they experienced was the loss of "intersubjective shared time". The sense of a shared experience is fundamental for the constitution of being. From this perspective, if our experience of time is fundamentally different to normative notions of time or what is expected of an able body, a sense of asymmetry between the self and the other takes place. Alterity, hence, precedes a feeling of disconnection and not belonging, when we stop being-together-in-time.

Alienation

The image of the "creeper", as so eloquently used by one of the participants to describe her pain, was perceived as something that at first was a reducible and circumscribed experience of the body that slowly starts to "creep in", pervasively, throughout the body. The boundaries of the body are gone, everything hurts, the body is pain and the horizons of experience are reduced to a single but general unpleasant sensation.

This is in line with Sartre's (1956/1992) turn of the consciousness, where pain ceases to be a bodily phenomenon and becomes instead a psychic object, an illness with a life on its own. Pain, in this case, made them feel their own bodies, revealing in its different manifestations the aches, the stiffness, the fatigue, which revealed the facticity and the otherness of their own bodies. As one of the participants expressed, she felt she was "living in someone else's body"; her body was not only an object but also a strange and unfamiliar one.

This alienating and domineering experience of pain, as illustrated in the findings, is accompanied by the notion that there is something wrong, and that the pain is the symptom and therefore the indication of illness. The more the pain sufferer needs to attend to her body as the body of “I cannot”, the more it becomes an object.

As the findings illustrate, there is a distance between the self and the body, the latter now an object governed by an external alienating force but at the same time inescapable, “feeling homeless in one’s own body” (Råheim & Håland, 2006, p. 753). The participants felt pain as something that came unannounced with an almighty force and with the power to bring their lives to a halt. Although theirs, the pain has a life of its own, giving it this alienating feature. Pain that can be described as essentially mine is at the same time beyond myself, uncontrollable, unreadable and unpredictable. The powerlessness and frustration were conveyed with each account, and the anxiety of the unknown and the uncontrollable was explicit and understandably scary. It is not just pain that they have to live with on a daily basis but also considerable fear: fear of the pain and suffering, the torture, the agony and the possibility of their bodies being seriously ill.

The narratives about pain also evoked the idea of an abductor making a hostage of the pain sufferer; they are prisoners of their pain, reduced and incarcerated in their bodies, restrained by the weight of their pain. Furthermore, there was also an element of submission and subservience in the sense that, when pain shows up, it needs to be attended to; nothing else and nobody else matters and the body is enslaved to pain’s authority. In this way, the findings concur with Scarry’s (1985) depiction of pain, understood as an authoritarian force that has the capacity to obliterate the sufferer’s personality and memories. Although Scarry’s study of pain is based on the phenomena of torture, experiences of overwhelming pain and chronic pain have the same features in the sense that pain is felt as inflicted from an external and inescapable source. This agent of pain is quasi-omnipotent and it has the power to reduce the subject to a bare body in pain and determine the way the world is experienced (Sik, 2021; Svenaeus, 2015). At the same time, when experiencing pain, we find ourselves in a situation of passivity since pain is felt as something that is done to us, torture inflicted by someone else or by our own bodies (Scarry, 1985). This was evidenced in one of the participant's accounts, who used the metaphor of a knife when describing her pain:

> I had this pain when I was talking to you, you feel like somebody is stabbing you, it feels like stabbing and somebody is turning the knife slowly. "Are you feeling it? Are you feeling it, yes, I'm feeling it!"

The omnipotent aspect of the chronic pain experience, as described in my findings, is felt like an imperative, whereby the pain resembles an authority whose command needs to be attended to in that precise moment and place. As Geniusas (2020) states, pain, much like hunger or thirst, needs to be attended to in order to protect the physical integrity of the sufferer. When the women experienced a flare-up, everything ground to a halt, and attending to their pain and physical needs was the most important priority. Despite wanting to rebel against it, and wanting to keep pushing, they inevitably had to surrender and abandon the world to be with their *"I cannot"* bodies. Abandoning the world was an experience charged with not only frustration but also deep sadness and grief, since their imperative demands of pain took them away from life, from their loved ones and the meaningful moments of life that are encountered in connection and belonging.

The lived-body – "I am not"

In this second section I discuss the impact of chronic pain on the embodied self, whereby chronic pain leads to a fundamental shift in the way the pain sufferers relate to themselves, their self-concepts, self-identity and self-relationship, pointing to a profound crisis characterised by loss and emotional suffering. Pain not only represents an assault on the body, as described in the previous section, but, as the findings illustrate, pain is also an assault on the self and the personality.

This second section corresponds to the dimension of the lived-body, or *Leib*, phenomenologically speaking. What was once recognised as the experience of the "I am" becomes the *"I am not"*, losing one's familiar way of being-in-the-world. Identities shattered meet the most profound meaninglessness and emotional suffering.

As observed in the accounts, the participants felt that they were no longer the same person they used to be; they went through a fundamental shift in their ways of being-in-the-world, this time represented by the experience of *"I am not".*

The alienating nature of chronic pain, as described earlier, led to fragmentation between the self and the body. In the first place, the self has a subjective expectation of what she can do with her body and how she wants to conduct herself in the world. Second, there is the objective experience of what the body can actually do. This was perfectly illustrated in the accounts where young participants felt trapped in an old body. Their selves were aware of their youth, their motivation, their need to connect with others, move freely and exercise their strength; however, their intentionality landed in a fragile body, which, at times of pain, seemed to speak a different language.

Unpredictable and unreliable

The unpredictability of the pain, and the time and place of it happening, was one of its most life-disrupting aspects. The participants found it very difficult to establish a specific pattern; they kept trying to understand the pain's behaviour in order to gain a sense of control but, despite all their attempts, the pain continued to behave in an erratic and unpredictable manner. The findings resonate with Juuso et al. (2011), who found that women with fibromyalgia were constantly "trying to endure an overwhelming feeling of unpredictability" (p. 4).

One of the consequences of this unpredictability was that the participants felt they were unable to plan ahead and commit to others; they were always worried about – the high possibility of –

having to cancel or reschedule their plans and disappoint other people such as family and friends, feeling unreliable in the eyes of the others. This was the case for Ruth, who had to cancel a family holiday because of her pain, waiting week after week to recover, which unfortunately happened too late. As well as having to live with the pain, she felt that her pain was inflicted on the rest of the family, which made her feel frustrated and powerless.

In addition, the women felt that they had to live their lives with caution, always bearing in mind that their pain might show up unexpectedly and that plans would need to be cancelled or rescheduled. This finding was mirrored by Rutberg and Öhrling (2012), who found that women with chronic migraine had to deal with a great amount of uncertainty caused by the unpredictability of their symptoms. This led to an experience of having to live their lives in a constant state of readiness as a way to adjust to the unpredictable nature of their condition.

The women's ability to commit affected not only their relationship with family and friends but also their employability. Almost the totality of the participants was unemployed, the reason for this being their chronic pain conditions. The unreliability of their bodies meant that they could not commit to their jobs, and those who were employed felt that their jobs were threatened by their extended sick leave. Despite wanting to work and having the desire to fulfil a meaningful dimension of their lives, they had to face the fact that their disability had no place in their occupational worlds. They also feared that the possibility of being selected for other jobs was highly unlikely. The literature also supports these findings, where it has been evidenced that women with fibromyalgia, although wanting to perform as well as they had done before in their workplaces, need to accept that they are unable to do so and that eventually they need to find other ways to find meaning (Juuso et al., 2016).

The unpredictability and its intersubjective counterpart of unreliability are the result of a fundamental lack of certainty, characterised by the not-knowing and personal and interpersonal mistrust. The way that pain behaves is hard to predict, which leads to the experience of a body that cannot be trusted and a sense of self that feels vulnerable in its unpredictability. Their being-in-the-world is stripped away of basic certainties, certainties shared by others, losing their capacity to foresee, expect and commit.

The loss of identity and meaning

As the findings revealed, the concept of identity is deeply affected by the experience of chronic pain. The women's identities are a reflection of what their bodies can or cannot do, and this is what sets the boundaries of the "I am" and how they relate to the world. It is through their bodies that they are able to fulfil the expectations of their specific roles and activities. Consequently, it is because they are able to fulfil these expectations that they can identify with these roles and self-definitions. Before the onset of the illness, this group of women succeeded in embodying their unique multi-layered identities. However, the ongoing pain turned their lived-bodies into something different, completely altering the sense of who they thought they were. This reminds us of Heidegger's (2010/1927) concept of "mineness": subjected to alienation in the experience of illness, the specific body that is, at the same time, a facticity is no longer recognisable.

The loss of identity and previous roles were evidenced not only in this study but in many others, as described in Chapter 2. According to most empirical evidence presented in the literature review, the lived experience of chronic pain in women has a significant impact on their identities. To provide an example of this, Wuytack and Miller's (2011) study on fibromyalgia found that participants experienced an existential crisis following their life-consuming disabilities, which leads to an identity collapse.

Aspects of the women's identity such as personality traits had also been affected by their pain. Those who once identified as extroverts, funny, active and social, have turned into someone different, no longer recognisable by themselves or others.

For Elena, one of the participants, this change in her way of being-in-the-world had serious repercussions on her social life, with her disability leading her to live a life of isolation when she was no longer recognised for who she was:

> Because people knew me differently, on my bike, exercising, cooking, festive, big parties, dancing, motivating everyone. Now it's the opposite. I'm on my own, I don't go out. My friends don't even call me to invite me anymore.

From most participants there was a clear sense of a constant struggle to maintain their before-pain identities, which meant having to endure daily tasks and activities despite the pain or other physical limitations, trying to remain active in order to fight the inadequacy of their bodies. The main consequence of this continuous fight against their pain and physical symptoms was a worsening of their condition, as well as feelings of inadequacy or being a failure.

Some women tried very hard to hide their pain when they were at work or with family members so they could preserve their healthy images despite the ongoing pain. They felt that their identities were threatened if they were not on top of things or behaving like they usually did. This was demonstrated in Shaefer's (2017) study on women with fibromyalgia, which found that secrecy was a common feature among the participants, who preferred to keep their pain and diagnoses to themselves in order to maintain a healthy image for their children and grandchildren.

The identity of "mother", whether this meant being one or the potential for becoming one, was considerably impacted by the experience of pain, since, according to the findings, being a mother goes hand in hand with the responsibility for providing ongoing care to someone who depends, or would depend, on their healthy bodies to do a "good job".

In their study Arman et al. (2020) provide a timely and excellent analysis of pain in women, placing important emphasis on gender relations and cultural context. Gendered roles and identity are particularly important when investigating the experience of chronic pain. It is paramount to understand the process of identity as something more than a subjective experience, since identity is the result of our social nature and can only occur in an interpersonal context. From this, it follows that the constitution and reconstitution of identity, particularly our gendered identities, are linked to our social and cultural context. From this also follows the fact that deviating from traditional gender stereotypes, such as being a caregiver or a mother, has led these women to feel once more at the margins of belonging.

Geniusas (2020) states that attunement or mood is an embodied experience, and it is through these moods that we can create meaning. Meaning is mediated by our bodies, and meaningfulness is, at the same time, also felt in the body. When the women of this study described feeling that their identities become narrower, to the extent that their being-in-the-world is governed by the experience of pain, meaning-making becomes impaired. The omnipresent and omnipotent nature of their pain makes the world disappear, and with it what they rendered meaningful, such as being a parent, travelling around the world, connecting with nature or their career ambitions. Scarry (1985), once more, would argue that pain, opposite to work, has a destructive nature and has the power to "unmake the world" (p. 41). Work, on the other hand, has creative power and makes the world existent through the doing. Work, although hard and painful at times, also has a purpose. From this point of view, pain can be transformed into a process of work that can provide a new source of meaning for the sufferer, especially when the pain is chronic.

Pain meaning-making, as well as adjusting and accepting, can be seen as forms of mastering the pain rather than giving in to it. This was illustrated in the findings, where many participants tried to find meaning within the context of this different and unfamiliar lived-body. Some of them tried to find the logic behind their pain, whether this was some form of emotional manifestation of biographical issues, or perhaps a message from the universe calling them to make changes in their lives. Accepting their pain led them to relate differently to it and to open their horizons of experience to new possible meanings. This can be exemplified by one of the participants, who showed hope and enthusiasm about the idea of creating a support group to provide advice and guidance to other fibromyalgia patients.

Dealing with chronic pain was described as a process of constant negotiation, whereby the processes of adjustment and acceptance are in an ongoing resignification. Although the experience of pain can provide an opportunity for meaning, it is also true that pain can leave life empty of meaning, filling it instead with suffering (Svenaeus, 2015).

From the findings, it was clear that the process of meaning-making and acceptance was not done in isolation, since it required, in all cases, the validation of others around the women. This could be from healthcare professionals, offering an appropriate diagnosis and treatment, as well as support from family and friends. Despite the loss presented by their disability, women who live with chronic primary pain can develop a positive sense of who they are with this new body and a newfound sense of self. However, this can only be achieved if they feel accepted, valued and respected by others.

Emotional suffering

Drawing once more upon Husserl’s (1989) ideas on embodiment, the subject is not merely a *Körper* but also a *Leib*, a lived-body. As Geniusas (2020) states, pain is neither purely physiological nor purely psychological. Independent of the cause, pain “is not reducible to the sum of its parts” (p. 155). Pain as an experience affects the lived-body and therefore it is possible to say that the other side of chronic physical pain is the emotional suffering resulting from myriad psychological experiences associated with the pain. These psychological experiences are not reduced to the intrapsychic phenomena but rather the result of a complex and dynamic interplay between the subjective and intersubjective worlds.

As described so far, chronic pain has an impact on the experience of the body and the self, with both realms being obstructed and affected by the limitations imposed. Physical pain is irrevocably mirrored by deep psychological suffering, which is not surprising considering the disrupted, or even lost, sense of self resulting from chronic pain. A body that can no longer engage with the world implies the pain of separation and not belonging. In the same way, chronic pain carries important losses attached to the different identities and roles that were embodied by a healthy body. In addition, the omnipresence of pain and the impossibility of imagining themselves as pain-free subjects imply that they have to grieve for an aborted future. Grieving for the lost self was a phenomenon shared by all of the women in the study, who, as well as having to physically relate to the world from a new body, also had to recreate a new sense of self. The latter is encapsulated in Toni’s words:

> And I have to grieve for the old me who used to be very active and loved the gym and loved to work and go out with the kids. I have now to change my whole way of thinking and my whole way of doing things.

In her study of vulvodynia, McCann (2015) observes that grief can be a common feature, in this case, attached to the uncertainty or almost impossibility of getting pregnant and becoming a mother. Although the latter was evidenced in some of the accounts of this study, the findings also show that the grief was not reduced to the loss of possible motherhood but extended into other areas of being, such as career expectations, hobbies and activities, that were meaningful in life. As most participants described, the possibility of exercising, dancing and cycling was taken away from them. These activities were not merely physical activities aimed at their health and fitness but forms of expression and intentionality. Exercise and movement were, for them, activities full of meaning, whereby physical movements transcended into a form of connection with others, with nature and will.

In accordance with the literature,[4] the women interviewed shared their feelings of guilt resulting from their inability to fulfil their old roles, feeling like they are, in a way, failing others who have to take on their responsibilities; husbands, children and their own parents have to help them with chores that they are no longer able to do. This is not only within the remit of their own homes but also at work, where colleagues have to cover for them during their absence.

Inferred from all the accounts were the feelings of shame and inadequacy about not fulfilling the standards of a healthy body and being different to what is considered the norm. As previously discussed, their bodies move not only in a different way but also at a different tempo; they are – and feel – slower than the rest, they need help from others, whether this is with the chores or with their finances, they need to justify their illness over and over again with different people and different settings, and they are questioned about whether what they suffer is real.

Chronic pain sufferers embody what Parsons (2010) called the “sick-role”, a socially institutionalised role type whereby the subject presents a deviant behaviour that excludes them from social obligations, being at the same time sanctioned by society. Pain, as observed, leads to isolation when the pain-bearer stops engaging with the world and the world of others as a result of the physical limitations, but also because of the feelings of shame or inadequacy, as illustrated in the findings.

As previously mentioned and observed in both the findings and the existing literature, women who suffer from chronic pain tend to hide their pain from others, when possible, in order to keep identifying themselves with a healthy body. However, it was also evidenced that the

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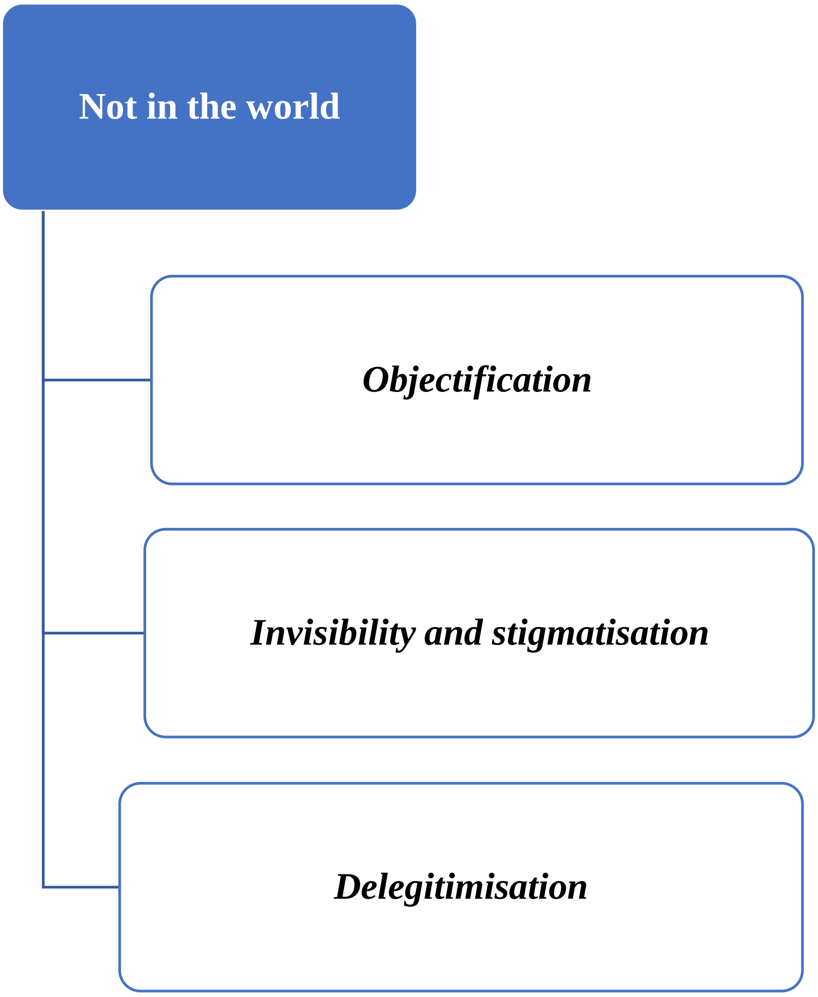
[4] Werner & Malterud (2003); Wuytack & Miller (2011); Clark (2012); Johnston (2013); Osborne (2008); Ramsey (2012); Råheim, & Håland (2006); McCann (2015); Gutke et al. (2018); Juuso et al. (2014); Rutberg & Öhrling (2012); Schneider & Fletcher (2008).

women chose – at times – to hide their pain from others or simply to play it down because they felt that when talking about their pain or other physical symptoms, they were seen as complainers or their character was being judged for not doing the right thing to get better. In the same manner, they also felt judged for having a contested diagnosis, not always understood by everyone. The feelings of shame, stemming from different assumptions about their pain and how their pain was perceived by others, were evidenced in the literature. An example of this can be found in Rutberg and Öhrling’s (2012) study on women living with migraine, where they observed that, in many cases, the participants worried about being seen as weak or lazy or as someone feigning illness. Similarly, the findings of this study also agree with Werner and Malterud (2003), who state that “illness has been shown to be experienced as a moral event, concerning shame and blame, responsibility and stigmatisation” (p. 1415).

Although the research to date does make reference to the emotional impact of chronic primary pain in women’s lives, it does not feel representative of the despair that the women conveyed during the interview encounter. Their depression was, understandably, profound, and thinking about or planning to put an end to their lives was not uncommon in the narratives, which can lead one to think that this other form of suffering has also been greatly overlooked.

Not in the world



From a phenomenological perspective, it is possible to say that the lived-body unfolds in the lifeworld “involved with other embodied subjects and in an intersubjective cultural world” (Thybo Jensen & Moran, 2013, p. vii). More importantly, the lifeworld is twofold since it is not only transformed by chronic pain but also held accountable for the way the experience of pain is lived and experienced by women.

This has a major implication for the experience of chronic pain since we could argue that the lived experience of pain is inescapably transformed by its situatedness. As Fullarton (n.d) states, more than a private and physical phenomenon, pain is “a negotiation between the individual and his or her greater social and interpersonal context" (p. 42).

In this intersubjective space, personal meaning is created about illness and pain. In this case, the result is questioning and invalidation of their experience; losing the essential aspect of world shareability, they feel *not in the world.* The latter is the result of three different processes: objectification, invisibility and stigmatisation, and delegitimisation, which will now be described.

Objectification

Phenomenological thinkers have made a clear point when stating that the body and the world constitute each other in a complex and dynamic way. Therefore, it is not possible to think of pain as a physiological experience; rather, as it has been described, pain is something that transforms the way we inhabit the world. Similarly, pain, as asserted by Jackson (2005), is not merely the private property of the individual who suffers from it. Pain also needs to be produced as a form of evidence, replacing what is regarded as a subjective experience with objectively verifiable data. Pain needs to be constantly evoked in the dialogue between the sufferer and those who can attend to it and treat it, giving it a moral and ethical dimension.

One of the most salient themes in the findings was related to the participant’s relationship with the medical professionals involved in the process of diagnosis and treatment. It became apparent that the patient–doctor relationship was perceived as a relationship where there was an attempt to objectify the experience of pain so it could be produced as evidence.

In this attempt to objectify the lived experience, the participants did not feel heard and understood, and when speaking to the different clinicians involved in their care, they felt that most of the time they, as women suffering from pain, were being objectified. Pain continues to be addressed as something that belongs uniquely to the physical body, with a failure to address its lived nature.

The experiences of objectification by another, mostly someone from the medical profession, were evidenced by the women of this study, who felt that they were being treated as *having* a body versus *being* a body. In Husserl's (1989) terms, the participants felt that healthcare professionals were relating more to a *Körper* than to a *Leib*, obliterating their lived experience and the different meanings that pain had for each of them. They listened to their symptoms but did not address the context whereby those symptoms were being enacted or lived. Evidently, there is a problem when pain is understood and treated from a biomedical model since it overlooks the fact that pain is a way of being-in-the-world. Conceived as a phenomenon that belongs solely to the body, the lived experience of chronic pain is expected to be revealed in a seven-minute consultation with a doctor and represented in a pain chart.

The relationship described so far fits into the category of the I-It attitude, as presented by Buber (1923/1958), where no distinction is made between a thing and a person. The relationship is dominated by objectivity, detachment and expertise on the part of the clinician. On the contrary, an I-Thou relationship is characterised by recognition and reciprocity, an encounter of mutual awareness that takes place in the dialogue. This last point seems fundamental for the analysis when considering that one of the most difficult aspects of the relationship with physicians has to do with the lack of opportunities to have an actual dialogue or encounter. Very short appointments, no eye contact, no interest in their views and no enquiries about their lived experience left the women's pain silenced and unattended, as one of the participants expressed: "I'd also like them to actually stop for a minute, stop writing, stop typing on the computer, look at me and listen to what I'm saying, that I am in pain, I'm in pain".

From this perspective, it is understandable that the women of this study had a different experience while taking part in this research, since, in contrast to their usual encounters with clinicians, they were offered the opportunity to talk about their pain at length and were met with curiosity and interest. Furthermore, they were invited to talk not only about their pain but also about their lived experience of pain, how it eroded different areas of their lives and how their encounter with meaninglessness led them to re-evaluate their lives. It was an opportunity for an I-Thou encounter. More importantly, this dialogue took place in a context of openness and what Buber (1947/2002) calls *inclusion*, or the capacity to experience an event from the position of one's self and the other at the same time. It was through this attitude that pain was allowed to come to the surface, to be expressed and shared with another. The participants felt listened to, and one should not overlook what the act of listening entails, which is recognising the values and specific meaning that pain has for the patient.

Much has been said about the non-shareability of pain and, although this is true in the sense that pain as a feeling can only be known by the one who experiences it, this does not imply that pain resists expression. Furthermore, as Stanier and Miglio (2021) state, it is through intersubjective encounters that the possibility for the pain to be shared and recognised arises.

This experience was not limited to the encounter with the participants during the research; they also expressed moments of shareability and recognition in other opportunities such as when meeting with complementary health professionals, loved ones and other people suffering from pain conditions.

Objectification and overlooking the fact that pain is a lived experience, as well as failing to create opportunities for dialogue so the pain could be shared, had negative consequences for the women of this study. First of all, the healthcare professionals failed to locate their symptoms within the phenomenology of a systemic functional illness, as was the case with fibromyalgia patients. Second, they were not able to understand the extent of their pain and its debilitating nature and how this was impacting their lives and the lives of others around them. This approach to their illness had serious implications for their diagnosis journey, as has also been demonstrated in the literature by several studies in cases of vulvodynia, endometriosis and fibromyalgia. To cite one of them as an example, Clark (2012) reported in her findings that the average delay time to receive a diagnosis of endometriosis was 12 years.

When chronic pain becomes not only untraceable but also misjudged and underestimated for a long time, as was the case for most participants, it fails to be legitimised. This is because legitimisation resides within biomedical narratives that need to objectify their pain to become real. This is in line with the empirical literature review, whereby receiving a diagnosis was met with relief and a sense of vindication, especially in the cases of fibromyalgia (Sturge-Jacobs, 2002), where participants had confirmation that their illness was not imagined.

One of the reasons for seeking a diagnosis was the expectation to receive adequate treatment and the possibility of making an informed decision with regard to their care. However, the women also needed a diagnosis in order to be acknowledged and recognised in their lived experience of pain, that what they were suffering from was real. Without a diagnosis, their pain remains delegitimised, which reminds us of Scarry (1985): "To have great pain is to have certainty; to hear that another person has pain is to have doubt" (p. 7). This is the inescapable paradox of the experience of living with chronic pain.

The lack of objective evidence is not the sole problem that the women encounter in their quest for a diagnosis. It is also the invisibility of their illness and pain that has compounded the lack of credibility and validation.

Invisibility and stigmatisation

A discursive practice that defines health and illness within the parameters of what is objective and evidenceable was not limited to the women's encounters with their doctors but also extended to other relationships. Having to prove to their family members and friends that they suffer from a real condition is at times challenging and even pointless for the women. Moreover, having to prove their illness at work or to governmental authorities such as the

Department of Work and Pensions for a Personal Independence Payment (PIP) is even more difficult. Not only do their conditions fail to show up in medical examinations but chronic pain also has the feature of remaining invisible to others since, most of the time, the patients look healthy on the outside, despite dealing with ongoing severe pain and associated symptoms. This is felt like a conflict for themselves and for others; as Sturge-Jacobs's (2002) study concluded, patients with fibromyalgia have to confront an invisible disability.

The lack of externalisation of the inner experience is not limited to their appearance but extends to the lack of possible objects of validation of illness. The participants felt that if they were in a wheelchair, had a cane, a walker or something external that signalled disability, their condition would be recognised as such and therefore their experience of the world that they inhabit would be different. This confirms Jackson's (2005) theory that these objects of disability, such as missing legs, pacemakers or hair loss due to chemotherapy, are a way to objectify reality under the Cartesian paradigm and grant full legitimacy to the experience, otherwise invisible. It was not surprising therefore when one of the participants expressed that chronic pain can be worse than cancer in the sense that at least the latter is acknowledged and treated with urgency and compassion.

Although the theme of invisibility was described in the literature review, the findings of this study extend the concept of invisible disability caused by chronic pain to include the invisibility of the mental health difficulties and struggles. As expressed by the participants, it is not only their pain that remains invisible but also the associated mental health deterioration caused by the pain. Many participants articulated having to deal with a double disability stemming from their pain and the effects of the latter. Their minds, as well as their pain, also occupy a place of liminality under the biomedical gaze.

Chronic pain sufferers have to endure the challenges and suffering posed by their disability; at the same time, the invalidation of their disability by the Other creates a profound and disorientating lack of attunement with the world.

There was a constant tension between having to prove their pain to others and at the same time having to conceal it to avoid stigmatisation for their “inappropriate pain behaviour”, as defined by Jackson (2005), and their unlimited “sick role” (Parson, 2010). Because, as well as the need for their pain to be legitimised by others, they were aware that the ongoing pain creates a sense of distrust among others, a feeling that they could in a way be responsible for their suffering.

As was the case with most of the participants, Jane preferred to conceal her pain from her friends:

> But if I’m with friends, I don’t like to say that I’m in too much pain. I don’t like it. Unless they kind of somehow know about it. Cause some people would say, “I don’t understand why are you always in pain”.

At the same time, the participants felt that looking good and concealing their pain at times had a detrimental effect, especially in the encounters with their doctors, who would tend to minimise their pain or have an impact on their pharmacological prescriptions. This confirms Werner and Materud’s (2003) observation that achieving the balance between looking well and unwell under the scrutiny of the medical authorities is the result of compliance with hidden rules between patients and doctors. This compliance is not exempt from a gendered discourse, whereby women are expected to socialise their pain differently from men within a context of structural forces of power of certain groups over others, as proposed by Butler (1990). In their encounters with their physicians, women “do” their femininity by engaging in activities and behaviours while remaining highly conscious of their body, the way they feel and the way others perceive them (Mason, 2010).

The objectification of experience, and the lack of credibility associated with the invisibility of their condition, result in what seems to be at the core of pain intersubjectivity, and this relates to the process of delegitimisation, which I will discuss next.

Delegitimisation

A fundamental experience of delegitimisation was identified in all of the accounts. This aspect is, without a doubt, one of the most salient features of the women's experience and one that is irrevocably linked to intersubjectivity. By delegitimisation, we refer to the systematic disconfirmation of experience, in this case, the systematic disconfirmation of the experience of illness, and thus an invalidation of their world. Delegitimisation seems to be a more suitable description than disbelief or dismissal, as approached in the literature. From this perspective, my findings place more emphasis on this unequivocal aspect of pain that was not evidenced in the literature search, which perhaps can be better articulated from the viewpoint of intersubjectivity.

Because pain could only become an objective reality through the medical discourse, whether in the form of a diagnosis, ultrasounds or bone scans, the participants' experience was inevitably subject to its power. The relationship between the woman in pain and the one who has the knowledge and power to treat it is therefore fundamentally asymmetrical. From this perspective, the women's power is limited to the medical discourse and framework where the consultation takes place, their role being to perform as credible patients (Werner & Malterud, 2003).

Accounts of power struggles were not absent in the narratives; on the contrary, a general feeling of disempowerment was conveyed. From the search for a diagnosis to their input in treatment decisions, the women of this study felt that not only were they not being understood but also that their views and opinions were not taken into account. Disempowerment was most evident in the pharmacological treatment options; it was a challenging position to be in for Vanessa, one of the participants, when her opinion was not taken into consideration and she had to face crippling pain on a daily basis: “I’ve looked at all the medication at all the next steps; I know what I need and nobody seems to listen to me.”

For Foucault (1963), medicine has the power to define reality through scientific knowledge that defines what is normal and what is not, defining at the same time what the embodied self is and creating discursive practices regarding what constitutes the experience of illness and health. The separation between the anatomical sign and the symptom led to a conception of illness, whereby the latter must show itself through pathological evidence. This creates a serious issue when there is a lack of objective pathological signs, as in the case of fibromyalgia. It is through this dominant discourse that demands medical evidence that this diagnosis becomes an object of medical and public doubt.

This specific discourse not only had a negative impact on the women’s diagnosis journey but also meant that, when diagnosed, they still felt doubted and unable to prove that their illness was real. The lack of tests to show, and evidence of the existence of pathology, left them feeling somehow confused and delegitimised.

The act of delegitimisation can take different forms, according to different narratives, with many studies supporting the finding that, in many cases, the women were told or made to feel that their chronic pain, such as fibromyalgia, was imagined or psychological (Söderberg et al., 1999). Although this was the case for one of the participants of this study, my findings challenge the fact that the psychologisation of pain by clinicians was a common feature. One could argue that, in recent years, more awareness and research on fibromyalgia has created more acceptance that this is not an “imagined” illness but a condition that simply cannot be evidenced through medical testing. Unfortunately, however, this has not resulted in a better care experience, since the participants of the study described being met with another form of delegitimisation; in the absence of objective pathology or signs of anatomical damage, their pain was dismissed by normalisation or underestimation of its severity. The fact that they could not see a broken bone, a concerning MRI or an altered blood test led clinicians to assume that in the invisibility of pathology pain should be somehow bearable and not so bad. Period pains, shooting, stabbing and unbearable pain are seen as a *normal event* under the medical gaze, as reported in Clark's (2012) study on endometriosis.

Understanding the delegitimisation of women's pain, whether by psychologisation or normalisation, has to be examined from a gender perspective since these conditions are, in most cases, exclusive to women. The dominant discourse of health and illness is not only a medical one, as Foucault (1963) states, but also a male one (Kvigne & Kirkevold, 2002); the representation of the world, including the world of health and illness is, in de Beauvoir's (1972) view, "the work of men" (p. 161). The main consequence of this is that the embodied self of a woman becomes an experience of Otherness.

The impact of a gendered medical discourse was implicit in the findings through the accounts of the normalisation of period pains, osteoarthritis pain and fibromyalgia pain by healthcare practitioners. Most women felt disappointed that conditions such as fibromyalgia and endometriosis were not well understood by their GPs, and one participant expressed that she had to educate the expert instead of the other way around. The women also felt disappointed that conditions such as fibromyalgia are so under-researched and that so little is known about its mechanisms and treatments. This has also been evidenced in most of the literature, where a lack of knowledge about fibromyalgia and women's health issues is commonly reported. Furthermore, Grundström et al.'s (2018) study on the experience of endometriosis states that women struggle to expose themselves, mentally and physically, only to be met with ignorance about their condition.

There was general acknowledgement that women’s health is more complex and that aspects such as hormonal changes can have an impact on the experience of pain and associated symptoms. The participants referred, on several occasions, to their periods, hormonal changes and the menopause. One participant felt confused about her symptoms regarding whether they were the result of fibromyalgia or menopause; both seemed to remain a mystery for clinicians. It seems interesting that research conducted on women’s health rarely accounts for the changes in hormonal fluctuations throughout the different stages of their lives. Consistently, this was not evidenced in the literature search that was conducted for this study.

The different manifestations of gratitude among the participants to the researcher for carrying out a study on the topic of women’s pain revealed their frustrations and the gap in the existing knowledge of pain conditions in women. This implies that their frustrations are not limited to the type of healthcare they receive but also to the way this healthcare has been informed by evidence-based practices, which do not hold enough knowledge about their specific conditions.

Delegitimisation led to deep feelings of shame that were revealed in the dialogue with the participants. The inability to prove their pain to others, and the fact that this pain was chronic, made them feel inadequate and unable to fit in. The way their pain has been conceptualised, the way others have responded to their pain and the different forms of delegitimisation have created an idea of a faulty self. The findings resonate with Sartre’s (1956/1992) dimension of the body for itself, as known by the Other, the uneasiness and shame of the woman in pain who experiences herself in the being-for-others, her body-for-itself, as known by another. One could argue then that, in the experience of pain, delegitimised pain, the sufferer is “vividly and constantly conscious of his body not as it is for him but as it is for the Other” (p. 353). Becoming oneself, in this case, is not only alienating because of the objectification done by the Other but also because that process of becoming a subject is fundamentally based on the nihilation of their experience of pain and the constitution of a for-itself that is faulty, ambiguous and liminal.

From a phenomenological point of view, delegitimisation of illness can be analysed in Husserl's (1931/1960) ideas on intersubjectivity and how subjectivity – in this case the subjective experience of pain and the constitution of its objectivity – can only be given by an ongoing intersubjective process. But this process, as Heidegger (1927/2010) would argue, is an encounter that occurs in the world; we encounter one another in a worldly situation, and our ways of understanding and being with one another are mediated by the meanings of the situated world.

It is only with this idea of the worldly situation that gender, previously absent in early phenomenological–existential thinking, becomes a fundamental structure of analysis.

de Beauvoir (1972) claims that when women are defined as "the other", they are being condemned to a state of immanence, the culturally and historically gendered place of women, which represents passivity and maintenance of life in its basic conditions. Reaching out into the future, creating, exploring, achieving, or, in other words, the project of transcendence, becomes unavailable in the experience of pain, whereby through the body itself and the oppressive discourses, the woman loses her freedom to project herself into the world. It follows from this that women who suffer from chronic primary pain capture Young's theory (2005), which states that a woman "often lives her body as a burden, which must be dragged and prodded along and at the same time protected" (p. 36). In this sense, these physical limitations represent women's natural tendency to immanence, whereby their bodies, motility and spatiality lose all possibilities for transcendence.

The way the experience of chronic primary pain unfolds in the lived world renders women an experience of *not in the world*. The radical experiences of pain, which are moderated by the situated lived world that they inhabit, are not only unseen or unheard but also disconfirmed and misconstrued, leaving their subjecthood in a place of passivity and subjugation. It is possible to say that it is through this intersubjective process of delegitimisation that their possibility for transcending to an intersubjective world becomes impaired, the thread that was used to connect them to others and the world is cut, and they are left adrift and ungrounded.

The impossibility of transcendence, the feeling of not being-in-the-world, results in a distinctive experience of isolation and separateness, represented in a profound loss of belonging.

Summary

The body, conceived as the lived-body, is incarnated in existence and is in continuous engagement with others and their environment. From this perspective, and as revealed in the analysis of the findings, the lived experience of pain is an engaged experience with the world, which paradoxically, and at the same time, represents a separation from the world.

What emerged from this hermeneutic enquiry is that chronic primary pain is a transformative experience that alienates the embodied self of the sufferer and her relationship with the world. Moreover, it was also revealed that their experience of pain was both constituted and transformed by the world that the women inhabit in the situated intersubjective encounters.

The purpose of this section was to evaluate the findings of this study within the existing literature and empirical evidence presented and to demonstrate how chronic pain is the pain of a fundamental separation from the world and the blockage of the project of transcendence. Pain shreds evidence of intersubjectivity, precisely through the disruption of the latter, the cessation of their being-in-the-world.

Critical evaluation and suggestions for future research

The decision to emphasise the intersubjective elements of the experience of chronic pain was an attempt to challenge the traditional understanding of this phenomenon as something quintessentially subjective and private. Pain defined in such terms – and nothing else – can have a detrimental effect on how pain is experienced by a subject, and this is why a special emphasis on intersubjectivity was considered relevant.

Studying intersubjectivity has been challenging from the beginning. Although a very relevant concept in phenomenology and other disciplines, intersubjectivity, a fundamental part of the lived experience, is implicitly assumed and usually taken for granted or limited to the interpersonal and relational dimensions. This was evidenced in the empirical literature review, where intersubjectivity was mostly embedded and, as such, assumed without further articulation.

Researching intersubjectivity implied a conscious and intentional effort to reveal this marginal aspect of the lived experience. It was an exercise of interpretation that sought to bring to light aspects of the lifeworld that were embedded and uncoded in the participants' narratives, through the constant balancing of the parts and the whole.

Although researching the intersubjective experience, this study has mainly focused on the participants' lived experience of their engagement with the world and, as such, this research can be criticised for having an individual bias, whereby the unit of analysis rests on the single individual. This, as some authors would argue, could impose the risk of overlooking the inter-psychological variables at play (Gillespie & Cornish, 2010).

In order to address this risk, the choice of a phenomenological hermeneutical methodology was made to ensure that intersubjectivity was at the core of the production of knowledge, by holding the assumption that meaning is essentially an intersubjective endeavour (Taylor, 1985), and to ensure that, instead of being seen as a dichotomy, subjectivity and intersubjectivity are mutually interdependent notions (Zahavi, 2011).

Given that this study is based on a phenomenological enquiry, it is possible to argue that the results obtained in this investigation are not to be generalised or understood as conclusive findings. Despite the intention of getting close to understanding a particular phenomenon, hermeneutic-phenomenological research will always be incomplete and its results only tentative. The meanings of the phenomena of chronic primary pain in women will always be open to different directions and interpretations and cannot be captured in their entirety. Similarly, they cannot describe the experience of all women with chronic primary pain, rather offering opportunities for further exploration and reinvention, being open to other voices.

The latter can, in a way, explain the small sample size, since the aim of the methodology is to provide more depth by generating exceptionally rich data, rather than large-scale and predictive descriptions.

Similarly, it could be argued that the sample population was geographically centralised since all of the participants lived in London, which might raise the question of whether the lived experience of women with chronic primary pain could differ if they lived in a different location. This perhaps could serve future studies that might be interested in exploring the influence of geographical differences in the experience of pain.

Following this line of thought, this study would have benefited from a more detailed analysis of structures of power other than gender, such as race, ethnicity and social class. The exclusion of these categories, particularly race, can unfortunately contribute to the systematic racial inequality in psychology research (Roberts et al., 2020). Similarly, although this study was limited to cisgender women, I am aware that trans people, who have also been systematically under-represented in scientific research, are at a great disadvantage when it comes to having their specific health needs met (Santora, 2021).

Given the importance of situated intersubjective elements in the discourses of health and illness, future research is needed in order to address the specific demands of an increasingly diverse society.

Throughout the writing process, I remained mindful of the limitations posed by language that can be perceived as a constraint in undertaking to convey what the intersubjective experience of chronic pain means. The dualism present in the language, when it comes to not only the mind/body reality but also other implicit dichotomies such as in/out, world/subject, has been a gravitational force that has been hard to escape. Despite these limitations, I strived to use a language that aimed to describe the experiences as something that resists reductionist categorisations, trying to convey instead its aliveness and relationality.

Because chronic primary pain is a new diagnostic category, there is a considerable need to conduct further research on the topic, especially as has been addressed, on other groups of society that tend to be less represented. Similarly, since chronic primary pain can include a wide variety of presentations, it is necessary to address whether this diagnosis is sufficiently representative and how this may have an impact on NICE (National Institute for Health and Care Excellence) guidelines and treatment outcomes.

Since this study has placed special emphasis on the intersubjective elements of chronic pain, it is clear that further research on chronic pain, as experienced by others, is needed. Since chronic pain can be understood as a shared experience that involves a process of negotiation between the pain-bearer and the pain witness, we need to understand more about what it is like to witness pain.

Research contribution and implications for clinical practice

Contributions to the field

In the previous section I addressed the limitations of hermeneutic-phenomenological research, the impossibility of fully understanding the phenomenon under study, and the limited generalisability of the findings. Therefore, when it comes to suggestions, I do not intend to make general prescriptive recommendations for care or to provide generalisations about what it means to live with chronic primary pain. Nonetheless, it is possible to say that a phenomenological enquiry can open up the possibility to promote a type of knowledge that, first of all, is reflective and, second, acknowledges the depth of the human situated experience. Following this, it is expected that this research will contribute to the generation of new horizons, adding to the existing corpus of knowledge in pain research and pain care that will enrich the understanding of chronic primary pain in women.

What I propose is an invitation to reflect on the experience of pain from a different angle. The general public, as well as most healthcare professionals involved in the diagnosis and treatment of chronic primary pain, would benefit from opening up their horizons when it comes to understanding pain. The dominant discourse of pain as an experience that resists communication and understanding has done nothing but reinforce this assumption, which is enacted in the encounter with the pain sufferer. From this perspective, the idea that pain is an enigmatic and impenetrable riddle is perpetuated, with patients and physicians hitting the same wall of frustration and powerlessness over and over again.

There is no doubt that pain, like all lived experience, is subjective in nature, which makes it an inaccessible alterity. But this quality is not exclusive to pain, since all subjective experience belongs to the Other and, no matter how much we try to grasp it, the knowledge about the other's mind will remain dubitable (Zahavi, 2011). We do not usually strive to seek evidence of subjective experience as much as we do with objective experience. The phenomenon of chronic primary pain is challenging because of its lack of objective evidence, resulting in the questioning of the subjective or lived experience of pain. By overcoming the suspicion of pain and approaching it from the assumption that pain is "whatever the experiencing person says it is, existing whenever and wherever the person says it does" (McCaffery 1983, p. 95), we can aim for an empathetic encounter that allows a mutual understanding. These are the moments that Stanier and Miglio (2021) describe as the intersubjective encounter, where it is possible for the pain to be shared and mutually recognised.

In other words, by the same processes that chronic pain is lived as separateness, it can be brought back, first and foremost, through the intersubjective encounter characterised by validation of the pain experience and a phenomenological understanding of what it means to live with chronic primary pain as a woman.

The phenomenological exploration of chronic pain provided in this study can provide new forms of understanding of the experience of women's pain through the lens of intersubjectivity. This means assuming a position where the pain is always real and situated. As well as the exhaustive pathological investigation, the healthcare practitioner can benefit from a hermeneutic-phenomenological enquiry, whereby the context of pain is investigated with the same dedication. In the case of women's pain, gender and sexual differences should always be considered and taken into account since they can be important determinants in the experience of pain. Specific gender roles do have an impact on how pain is lived and how it affects women's lives in different ways compared to men, for example. As one of the participants pointed out, "women take more on 'cause we are mothers. Also, there are more women in this world with children on their own than fathers". The data shows that in the UK, in 2019, 14.9% of families in the UK were lone-parent families and 86% of this group were lone-parent mothers (Office for National Statistics, 2019). Being aware of this type of socio-demographic could potentially benefit the understanding and care path of chronic primary pain. Similarly, medical professionals should recognise that many conditions that affect women, such as chronic pain, gynaecological disorders and autoimmune diseases have, compared to those affecting men, been considerably under-researched. Medical practices could take into account, for example, the role of female hormonal changes throughout life and their specific link to the experience of pain. There is little research on the relationship between menopause and chronic pain, and if – still – little is known about menopause, less is then known about the fact that midlife women with menopausal symptoms are more vulnerable to chronic pain (Gibson et al., 2019). I saw this reflected in the participants’ experiences, in them feeling let down by doctors but also by science, feeling forgotten and misunderstood. In response to this, one can only observe that there is an evident gap in women’s health research that needs to be acknowledged and hopefully addressed so that this lack of knowledge is not reflected in patient care outcomes, as is currently the case.

I am, of course, aware of the current limitations of our health system and how it is struggling to cope under the growing pressure on the different services. Asking for the time needed to get acquainted with the patient’s lived experience, with their *Leib*, seems unattainable when more needs to be done in less time. But the reality is that patients with chronic primary pain do need a long consultation and, although it can be costly in the beginning, it can become a cost-effective measure in the long term. Furthermore, it is not only time that these patients need. An understanding of pain within an intersubjective framework allows the phenomenon to be approached as something that belongs not only to the patient but also to the medical, societal and political contexts. Pain garners meaning in the intersubjective context.

Medical practices and training should address and consider the effect that poverty, migration, gender-related violence, ethnic conflicts and ongoing discrimination have on women’s health. The validation of pain requires critical thinking and challenging views, such as the one offered by this study, so that the voices that have been silenced by dominant paradigms in institutions and societies can be heard and revealed.

To summarise, it is possible to say that the intersubjective encounter between the patient and the pain physician could be reconsidered and perhaps reformulated, thus allowing for an enquiry that permits the narrative to be co-created respectfully and meaningfully in what Buber (1923/1958) would describe as an I-Thou encounter. This task should not be limited to the mental health professionals involved in pain management, since, as one of the participants shared, they need to feel listened to first of all by their pain doctor.

Contributions to clinical practice

The role of psychological therapies is widely recognised in modern pain management, guided most of all by evidence-based practices. Under this category, the main psychological interventions fall under the umbrella of cognitive–behavioural therapies, which are mainly interested in pain behaviour and the private thoughts and feelings involved in the pain experience. Similarly, most of the research on psychological interventions for pain has been dominated by the same discipline. Psychodynamic theories have also had a place in understanding and treating chronic pain, and the link between psychological trauma and abnormal somatic experience continues to offer plausible explanations for the phenomena. It is not my intention to expand on the contributions and weaknesses of these approaches, and both cognitive–behavioural and psychodynamic theories have much to offer in pain management. Nevertheless, the findings of this study reflect that some important elements have been overlooked in the psychological approach to pain and, in my view, this stems from the assumption that pain is mostly private and subjective.

This study presents a phenomenological enquiry into the experience of pain and offers the opportunity to understand how pain impacts the embodied self and therefore its relationship with the world. Psychological approaches can challenge Cartesian paradigms precisely by acknowledging the lived embodied experience of illness and how a disabled body inhabits time and space in relation to the world and the world of others.

Furthermore, this research emphasises the urgent need to create more awareness regarding the different structures involved in the construction of pain. This study has touched upon themes of gender inequalities when it comes to women's health in medical research and practice. Mental health practitioners need to bear in mind the impact of the problems of patriarchy and how this affect both men and women, instead of being silenced and overlooked.

A psychological approach that fails to legitimise the personal experience of pain will perpetuate the feelings of powerlessness and helplessness that result from previous delegitimising encounters. One can assume that the psychological practitioner can easily avoid this trap; nevertheless, the processes of normalisation, objectification and delegitimisation can also take place in the therapy room. From a phenomenological standpoint, it seems paramount to offer the pain-bearer the possibility to present her own story so that the meanings can emerge and her experience can be met and genuinely confirmed by another. The skills needed to achieve this may not only help the subject in pain but can also be transferred to healthcare practitioners, who can considerably benefit from this.

Lastly, and very importantly, psychological practitioners should, and must, be aware of the depth of the emotional impact that chronic primary pain can have on someone’s life. The mental health issues resulting from the pain experience can be extremely disabling and can also carry a significant suicidal risk, which requires monitoring and holistic intervention. Moreover, it seems important to bear in mind that physical pain is not the single thing responsible for their suffering. Stigmatisation, delegitimisation, invisibility, dismissal, mistrust and delayed diagnoses have a significant and damaging impact too. These things are neither subjective nor private but the result of ongoing encounters and interactions with others, the intersubjective realm that we inhabit and which informs the way that we encounter pain and suffering.

CHAPTER 6: CONCLUSION

The phenomenon of pain confronts us with the tension existing between the dualities of the objective/subjective, as well as the mind/body split. The fact that we believe that pain cannot be expressed in simple language because of its complex and complicated nature results in the assumption that pain is an essentially private and subjective experience. With the aim of challenging this dominant assumption and tension between an objective versus a subjective approach, and perhaps offering a new form of understanding pain, this study set out to address the intersubjective elements in the experience of chronic pain in women.

Influenced by my existential-based training as a counselling psychologist, I approached it from a phenomenological standpoint, which allowed me to, first of all, challenge the limited views of pain often conceived as something private and ineffable. Second, through an existential–phenomenological position, I placed particular emphasis on the way that pain is experienced as a way of being-in-the-world. Without underestimating the fact that the subjective experience of the other is inaccessible to me, I was able to witness the fact that pain *does* open to the world. In order to gain access to this openness, to render what is considered invisible visible, I encountered eight women, who generously and courageously allowed me to enter and participate in their experience. It was expected that, through a phenomenological interpretation of their descriptions of chronic pain, the reader would get acquainted with the way that chronic pain is lived in a world that is shared and situated.

As a lived experience, chronic pain unfolds in a relational, social, historical and political context, providing both intersubjective and personal meaning. In the same way, the relationality with the world is given through an embodied fashion that is blocked by a “deficient” body, in disharmony with the laws of space and time.

Gaining access to this knowledge was made possible thanks to the embodied and relational encounter that I had with the participants and what emerged in the intersubjective space. The felt sense of embodied empathy (Finlay & Evans, 2009) that was offered during the interviews was the key to entering what is deemed private and inaccessible. This was the moment that their pain not only became visible but also confirmed in its reality.

The reality of their pain was also the reality of their suffering and alienation. The thread that connects to the world, if not severed, was held by waning fibres that spoke of a profound loss of belonging and isolation. And that was the painful paradox of their existence, the fact that they are in the world but at the same time so separated from it. The separation is, in part, the result of the limitations imposed by their bodies and the imperatives that pain imposes on them. The splitting off from the world also comes from receiving the message that something is wrong with them, that they are somehow faulty, physically, mentally and morally.

Unfortunately, this is not an uncommon phenomenon for women who have historically faced the effects of systemic institutionalised patriarchy. The delegitimisation of their pain experience – whether through psychologisation, normalisation or knowledgelessness about women's health and women's pain – contributes to the feelings of inadequacy and therefore not belonging. It is undeniable that the effects of patriarchy are not limited to women and that sexism has repercussions for all genders. Nevertheless, the current research supports the view that gender health inequalities are unfortunately having a severe detrimental effect on women's well-being.

It seems important to acknowledge that this research journey has taken many turns since its onset. Nonetheless, since its embryonic stages, the braid of this research has been woven with three constant strands – women, health and care – and, surrounding them, innumerable academic writings, women's voices, books, poetry, films, meditation, conferences, personal therapy and supervision. Underneath this has been the growing discomfort brought about by awareness, awareness of the powerlessness of the ethical demands posed by pain and suffering, the inequality, the uncertainty, the sadness and frustration. All of this was knowledge, some to be bracketed, some to be interpreted and written. I gained knowledge about women's health, the care, and lack of care, that they receive from others, and how pain is borne not just by these women but also by the people they love and the society they live in.

I am hopeful that the findings presented here will be of use and able to contribute to the existing body of knowledge regarding chronic pain in women.

Throughout the years, the understanding of pain, as well as the phenomena of health and illness, have slowly been redefined and approached more holistically, resulting in bio-psycho-social models of health. Yet, pain continues to confront us with further dilemmas: medical, psychological, ethical, social and political. Following this line of thought, I was inspired by the work of Nicholas Maxwell (2019), a British philosopher who argues for the need to replace the acquisition of knowledge with the promotion of wisdom by rational means, as the main aim of science and academic enquiry. In order to avoid the global crises resulting from science without wisdom, we need to acquire more of the latter so that science can help to resolve conflicts and problems in a cooperatively rational way.

At the time of writing this chapter, there are several war conflicts in the world, including here in Europe. The COVID-19 pandemic continues to take lives daily and we are facing the devastating effects of the climate crisis. The urgency conveyed by Maxwell could not be timelier; now, more than ever, science and the academic world need to redirect their efforts to attain social wisdom. I see this wisdom represented in the voices of women who have been dismissed and let down by research (Criado-Perez, 2019) and who need to be listened to so that their stories and lived-experiences can be brought to light.

I sincerely hope that the knowledge presented in this study is translated into wisdom so that it is used to provide something of value for women who suffer from chronic primary pain.

The necessity for wisdom in academic enquiry reminded me of the Buddhist saying that a bird needs two wings in order to fly. The first wing, wisdom, the deep penetration into the nature of reality, is not enough without the other wing of compassionate action, which seeks to alleviate suffering by helping to create changes in our society that will no longer perpetuate that suffering. And as the last strand of the braid of this study, my commitment to care will not stop here. My aim, as part of my personal and professional journey, is to continue to engage with women's rights and particularly women's health inequality.

Pain, without a doubt, represents an imperative demand for care. It enters the ethical sphere the moment we become a witness to it. Friends, relatives, partners and healthcare practitioners – we cannot escape the pain of others. At some point, we will always be faced with another's pain, whether welcome or not.

As Gantt (2000) states, suffering is never a private or individual matter since it is always experienced by more than one person. More than a solely subjective experience, suffering is also a social and moral phenomenon, involving the sufferer but also those who are called upon to respond to that suffering, answer for it and care for it. Suffering is an intersubjective constructed and negotiated product of interrelatedness and the responsibility we have for one another.

So, when we care about pain, what do we mean by that? How do women know that others care about their pain?

I conclude this reflection with something that I consider to be a starting point in the fields of women's chronic pain research and care: to question what we all know to be true, what we never challenge. We all know that we care, but really, *how* do we care?

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APPENDICES

1. Table of studies reviewed for Literature review

2. Research Flyer

3 Participant Information Sheet

4. Prompt interview questions

5. Consent form

6. Debriefing sheet

7. Analysis procedure – Pilot interview transcript

8. Configuration of the themes

Appendix 1 -Table of studies reviewed for Literature review

	TITLE	COUNTRY	AUTHOR	YEAR	SAMPLE SIZE	METHODOLOGY
1	Women's Lived Experiences of Chronic Pain: Faces of Gendered Suffering.	Sweden	Arman, M. Gebhardt, A. Hök Nordberg, J. Andermo, S.	2020	21	Hermeneutic Analysis
2	Experiences of women with endometriosis: an Interpretative Phenomenological Analysis.	United Kingdom	Clark, M.	2012	13	IPA
3	Pelvic girdle pain affects the whole life--a qualitative interview study in Norway on women's experiences with pelvic girdle pain after delivery.	Norway	Engeset, J. Stuge, B. Fegran, L.	2014	5	Hermeneutic Phenomenology
4	Adaptation to a changed body. Experiences of living with long-term pelvic girdle pain after childbirth.	Sweden	Gutke, A. Bullington, J. Lund, M. Lundberg, M.	2018	9	Empirical phenomenological psychological method
5	The double-edged experience of healthcare encounters among women with endometriosis: A qualitative study.	Sweden	Grundström H. Alehagen, S. Kjølhede, P. Berterö, C.	2018	9	IPA
6	Women's experiences of vaginismus and its treatment: an interpretative phenomenological analysis.	United Kingdom	Johnston, S.L.	2015	3	IPA
7	Living with a double burden: Meanings of pain for women with fibromyalgia.	Sweden	Juuso, P. Skär, L. Olsson, M. Söderberg, S.	2011	15	Hermeneutic Phenomenology

8	The Workplace Experiences of Women with Fibromyalgia.	Sweden	Juuso, P. Skär, L. Sundin, K. Söderberg, S.	2016	15	Hermeneutic Phenomenology
9	Meanings of being received and met by others as experienced by women with fibromyalgia.	Sweden	Juuso, P. Skär, L. Olsson, M. Söderberg, S.	2014	9	Hermeneutic Phenomenology
10	Towards a better understanding of the lived experience of vulvodynia and its impact upon gender identity: An interpretative phenomenological analysis.	United States	McCann, E. W.	2016	12	IPA
11	The effects of symptomatic endometriosis on womanhood.	United Kingdom	Osborne, S.F.	2008	7	IPA
12	Living with chronic migraine: a qualitative study on female patients' perspectives from a specialised headache clinic in Spain.	Spain	Palacios-Ceña, D., Neira-Martín, B., Silva-Hernández, L., Mayo-Canalejo, D., Florencio, L. L., Fernández-de-Las-Peñas, C., García-Moreno, H., García-Azorín, D., & Cuadrado, M. L.	2017	20	Qualitative phenomenological study
13	Lived Experience of Chronic Pain and Fibromyalgia: Women's Stories from Daily Life.	Norway	Råheim, M. Håland, W.	2006	12	Hermeneutic Phenomenology
14	Living with migraine headache: a phenomenological study of women's	United States	Ramsey A. R.	2012	8	Phenomenological enquiry

	experiences.					
15	Migraine--more than a headache: women's experiences of living with migraine.	Sweden	Rutberg, S. Öhrling, K.	2012	10	Hermeneutic Phenomenology
16	The lived experience of fibromyalgia in African American women.	United States	Schaefer, K.	2005	10	Phenomenological method (Van Manen)
17	I feel as if my IBS is keeping me hostage!’ exploring the negative impact of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) upon university-aged women.	Canada	Schneider, M. A. Fletcher, P. C.	2008	7	Phenomenology and Heuristic Enquiry
18	Women's experiences of vulvodynia: a meta-ethnography of existing literature and an interpretative phenomenological analysis of the journey towards diagnosis.	United Kingdom	Shallcross, R. Dickson, J. Nunns, D. Taylor, K. Kiemle, G.	2015	8	IPA
19	Struggling for dignity: the meaning of women's experiences of living with fibromyalgia.	Sweden	Söderberg, S. Lundman, B. Norberg, A.	1999	14	Hermeneutic Phenomenology
20	The experience of living with fibromyalgia: confronting an invisible disability.	Canada	Sturge-Jacobs M.	2002	9	Phenomenological method (Van Manen)
21	Social support for women with chronic pelvic pain.	United Kingdom	Warwick, R. Joseph, S. Cordle, C. Ashworth, P.	2004	8	IPA
22	It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors.	Norway	Werner, A. Malterud, K.	2003	10	Phenomenological Analysis
23	The lived experience of fibromyalgia in female patients, a phenomenological study.	United Kingdom	Wuytack F. Miller P.	2011	6	Descriptive Phenomenology

Appendix 2 – Research Flyer

Are you a woman experiencing chronic primary pain?

Volunteers Needed
for Doctoral Research into:

The lived experience of women with chronic primary pain.
Conducted by DCPsych Student: DCPsych in Existential Counselling Psychology and Psychotherapy

The purpose of this research is to understand the lived experience of women who suffer chronic primary pain; chronic pain in one or more anatomical regions that is characterized by significant emotional distress and functional disability.

If your:

- Pain is characterised by significant emotional distress (anxiety, anger/frustration or depressed mood)
- Pain is characterised by functional disability (interference in daily life activities and reduced participation in social roles)
- Pain has been experienced for over a year, with unclear etiology or diagnosis.

And if you:

- Live in Greater London
- Are able to communicate in English

You might be interested in taking part in my research.

Your participation will involve a 60-90 minutes interview and will be focused on your unique experience of pain and, the physical, emotional and social impact this has on your life as well as the experience of having to talk about your pain.
The research project has received a full ethical approval from the New School of Psychotherapy and Counselling, and Middlesex University ethics panel.

Please contact Catalina at womenchronicpain@gmail.com or on phone number: 07507116985 for further information.

Appendix 3 – Participant Information Sheet

PARTICIPANT INFORMATION SHEET

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August 2019

Researcher
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Supervisor
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Research Title

The intersubjective experience of women with chronic primary pain

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why this research is being done and what it will involve. Please take your time to read the following information carefully, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part in this study.

Research aim

The purpose of this research is to understand the intersubjective experience of women who suffer chronic primary pain; chronic pain that is characterized by significant emotional distress and functional disability. The study will focus on your unique experience of pain and, the physical, emotional and social impact this has on your life. This will then be analysed from a relational perspective. This means that I will be paying attention to the encounter between us and the meanings we create together.

What can you expect if you decide to participate?

If you decide to participate, you will be asked to take part in an interview that should not last more than ninety minutes. The interview will take place in a private psychotherapy room in North London or a suitable location closer to your home if travelling is difficult for you, at a date and time that is convenient to you. During the interview, we will have an informal dialogue about your experience of chronic pain. Two digital voice recorders will be used to record the conversation and this will be destroyed immediately upon transcription. Your data will then be stored on an encrypted memory stick on the researcher's personal computer and any identifying data stored in a locked cabinet in the researcher's own home.

Your personal information and recording

All the information you provide will be anonymised so any names or identifying information will be changed or removed in order to assure your privacy. The findings from this study will be shared with other researchers and may also be published in peer-reviewed journals.

Support and right to withdraw

Talking about your experience of pain and contributing to a greater understanding about this topic, which may eventually help others who suffer from the same condition, can be an interesting and rewarding experience. However, some people may find talking about this, difficult and upsetting. Please do share your feelings with the researcher and if you find yourself feeling upset, the recording will be stopped until we can make sure that you are ok. The interview will continue only if and when you want to.

What happens next?

Before you take part in the research, you will be given a copy of this information sheet and asked to sign a consent form. This in no way obligates you to take part and you may withdraw at any time up until transcription of your data and without any obligation to explain your reason. If this is the case, all the information and data collected to date, will be destroyed and your name removed from the study.

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The Middlesex Psychology Department's Ethics Committee have reviewed and approved this proposal.

Thank you for reading this information sheet carefully. Here are the contact details of the members of this research:

Researcher
Catalina Mena - CM1471@live.mdx.ac.uk
NSPC, 61-63 Fortune Green Road, London NW6 1DR
+44 (0) 2074358067

Supervisor
Dr Neil Lamont - lamontneil@hotmail.com
NSPC, 61-63 Fortune Green Road, London NW6 1DR
+44 (0) 2074358067

Appendix 4 – Prompt interview questions

1. Can you tell me a bit about your pain, how long have you had it for?
2. What is it like for you to be in pain?
3. What is it like to be with other when you are in pain?
4. What is it like when you have been with doctors, or other healthcare practitioners?
5. What is it like to be in pain when you have been at work?
6. What is it like to be in pain when you are with your family and friends?
7. How do you feel that others respond to your pain?
8. Do you feel that your pain affects others?
9. Is there something about being a woman that makes your experience different?
10. How have you felt so far, during the course of this interview?

Appendix 5 – Consent form

Middlesex University School of Health and Education
Psychology Department
Written Informed Consent

Title of study and academic year: “The intersubjective experience of women with chronic primary pain” – August 2019
Researcher’s name: Catalina Mena Garces CM1471@live.mdx.ac.uk
Supervisor’s name and email*:* Dr Neil Lamont nspcneil@gmail.com

- I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.
- I have been give an Information Sheet outlining the nature and aims of the research to take home.
- I have been given contact details for the researcher and her supervisor in the information sheet.
- I understand that my participation is entirely voluntary, that data collected during the research will not be identifiable, and that I have the right to withdraw from the project at any time up until transcription of the interview without any obligation to explain my reasons for doing so.
- I understand that I will be fully debriefed following the interview and given a list of agencies and support groups to take home.
- I further understand that the data I provide will be used for analysis and possible publication, and I provide my consent that this may occur.

____________________________ ____________________________
Print name Sign Name

Date: ___________________________

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Health and Education Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: ___________

Appendix 6 – Debriefing sheet

Psychology Department
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London NW4 4BT

New School of Psychotherapy
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The intersubjective experience of women with chronic primary pain

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Thank you very much for taking part in my research. The present study has been designed to explore women's intersubjective experience of chronic pain and the impact it has on their lives.

Your contribution to the study is extremely appreciated and will help to inform clinical decision making and facilitate chronic pain patients' outcomes.
For your information, the recording of this interview will be destroyed immediately upon transcription. Your data will then be stored on an encrypted memory stick on the researcher's personal computer and any identifying data will be stored in a locked cabinet accessible only by me.

I hope you have understood the aim and purpose of this study and enjoyed your participation in it. I would like to take this opportunity to encourage you to get in touch with me if you have any queries or questions regarding the research.

In the same way, in case you wish to explore any issues that have arisen for you as a result of your participation in this study, you can refer to the list of Organisations and Support groups listed below.

- Pain Concern UK www.painconcern.org.uk
- *Pain Support UK* www.painsupport.co.uk
- Chronic Pain Support www.chronicpainsupportgroup.co.uk
- Action on Pain www.action-on-pain.co.uk
- Fibromyalgia UK www.fmauk.orgUK Fibromyalgia www.ukfibromyalgia.com

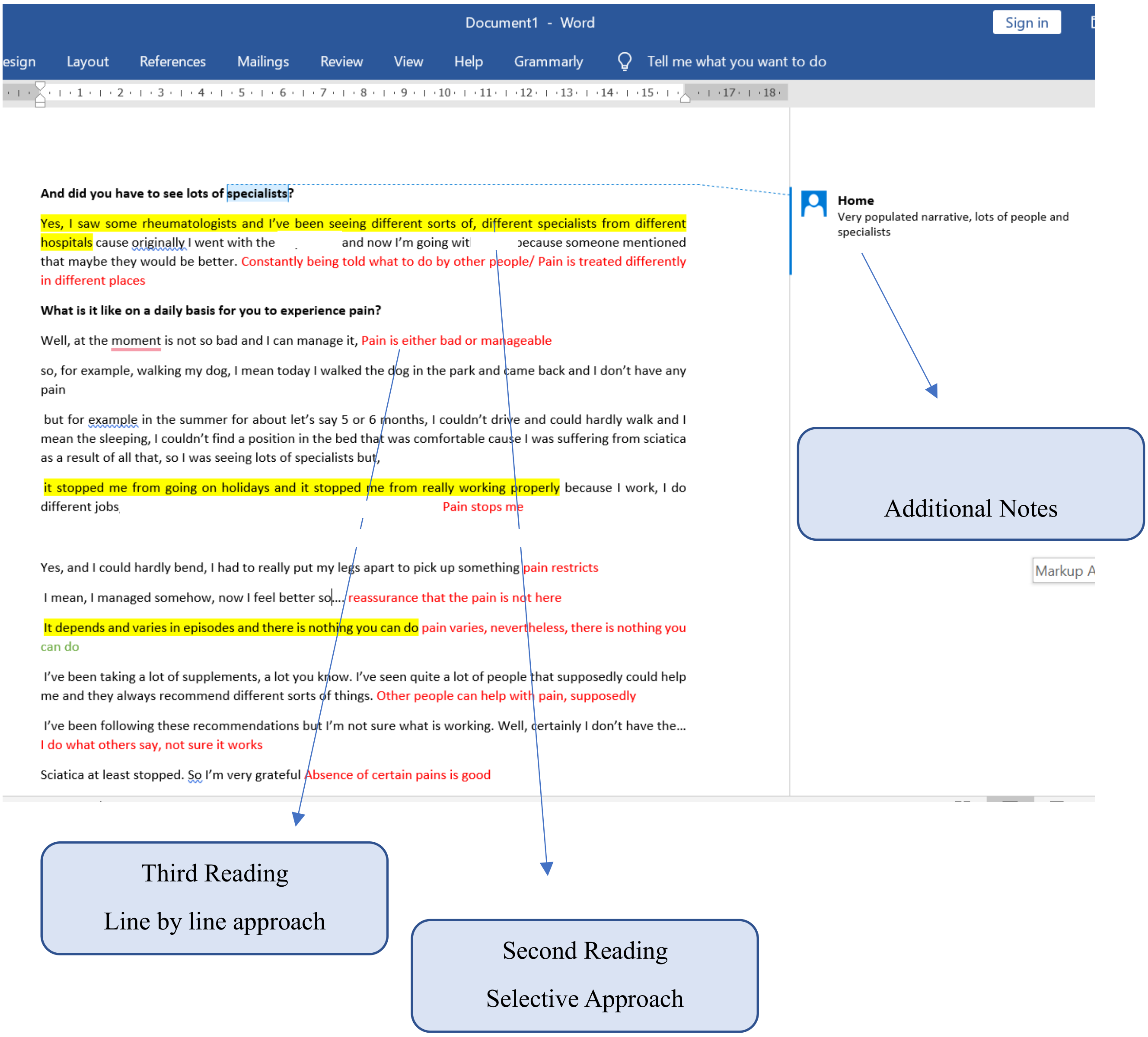
For psychological support:

- NHS – IAPT Services http://www.iapt.nhs.uk/services/
- MIND http://www.mind.org.uk
- ReThink http://www.rethink.org or call 0300 5000 927.
- Spiral Centre http://spiralcentre.org/low-cost-therapy/
- Centre for Better Health http://www.centreforbetterhealth.org.uk

Thank You again for taking part.

Appendix 7 – Analysis procedure – Pilot interview transcript

Part 1



And did you have to see lots of specialists?

Yes, I saw some rheumatologists and I've been seeing different sorts of, different specialists from different hospitals cause originally I went with the and now I'm going wit ecause someone mentioned that maybe they would be better. Constantly being told what to do by other people/ Pain is treated differently in different places

Home
Very populated narrative, lots of people and specialists

What is it like on a daily basis for you to experience pain?

Well, at the moment is not so bad and I can manage it, Pain is either bad or manageable

so, for example, walking my dog, I mean today I walked the dog in the park and came back and I don't have any pain

but for example in the summer for about let's say 5 or 6 months, I couldn't drive and could hardly walk and I mean the sleeping, I couldn't find a position in the bed that was comfortable cause I was suffering from sciatica as a result of all that, so I was seeing lots of specialists but,

it stopped me from going on holidays and it stopped me from really working properly because I work, I do different jobs, Pain stops me

Yes, and I could hardly bend, I had to really put my legs apart to pick up something pain restricts

I mean, I managed somehow, now I feel better so... reassurance that the pain is not here

It depends and varies in episodes and there is nothing you can do pain varies, nevertheless, there is nothing you can do

I've been taking a lot of supplements, a lot you know. I've seen quite a lot of people that supposedly could help me and they always recommend different sorts of things. Other people can help with pain, supposedly

I've been following these recommendations but I'm not sure what is working. Well, certainly I don't have the... I do what others say, not sure it works

Sciatica at least stopped. So I'm very grateful Absence of certain pains is good

Part 2

FIRST READING THEME	**VERBATIM**
Lack of control over body, lack of control over life and future. A life of uncertainty.	*I mean is the fact that it comes insidiously in your life, without you knowing it and sometimes you don't have the control of it and that's the thing, is the lack of control I suppose what is the most painful thing and talking about it … yeah…makes me realise that's the main issue really, is the lack of control of your own body.*
SECOND READING THEMES	**Highlighted Statements - Verbatim**
Theme 1 - Accepting and adapting to a life with pain	*Yes, that's right, the core pain is not taken away* *I think now, I've got to manage the pain* *there's not much you can do…. take some painkillers* *I just will have to find the way of managing it.* *that I am adapting myself to a certain degree to the pain* *been thinking of doing all sort of other things that don't involve so much my body and I'm quite happy about it* *Certainly, with my body, before I could do more things, or be more adventurous, yes, now I'm more careful.* *Yes definitely, it's just accepting it, you can't fight it somehow but you can have a hip replacement (laughs)* *It depends and varies in episodes and there is nothing you can do* *"pain of the day"*
Theme 2 - I can't be for others when I'm in pain. Pain demands my full attention	*In a way I rather spend time with myself or you know [when in pain]…* *…. I feel quite sad about it, cause it makes you, you know, go back into yourself* *Yes, so you are not really there,* *Different places, and I'm sure it was annoying to be around me because I was not fun and I could see, because I didn't want to do this I didn't want to do that* *not fully there for him because part of me is looking after my side so I have less time, less attention,* *They get annoyed with me or you know, they don't engage in the same way* *Exactly, that's why I don't want to impinge on people's life as well because I can't operate normally, they rely on me for certain things and I'd like them to do it for themselves but if they can't they are waiting for me* *But yes, I think the worst bit is to feel that I've let down people especially my daughter who is only 13* *so I haven't been able to be with her fully because I was in pain and that's the most painful thing almost you know, (…)* *or with my partner I can't be with him fully because I'm in pain and I can't really engage.* *but for me it's been mainly with my daughter, sometimes I'm tired and I can't help her with homework or I can't do this or that, if I want to do the cooking, maybe you need an ingredient and you can't be bothered to go to the shop cause you are in pain. Its little details but it does change the texture of your life somehow.* *I think pain makes you retreat, because you can't really concentrate when you are in pain*
Theme 3 - Uncertainty about the body's response create a sense of lack of control	*It's the uncertainty that… and also when it flares up, you become even more uncertain because you don't know how things are going to turn up* *You can't really make commitments or your commitments are not so…* *is always there, something nagging you and you don't know what to do really, you don't know when is going to stop, you don't know…*

	if you knew when is going to stop maybe you could plan things. Because you don't know you really have to live on the spur of the moment, so maybe it makes you live more in the present but even if you live more in the present you may be scared of doing something because you worry that the pain will be triggered *You know I'm quite resourceful in that way, but having said that, it is quite frustrating as well and sometimes I feel more frustrated* *I mean is the fact that it comes insidiously in your life, without you knowing it and sometimes you don't have the control of it and that's the thing, is the lack of control I suppose what is the most painful thing and talking about it … yeah…makes me realise that's the main issue really, is the lack of control of your own body.*
Theme 4 - Being with other in pain means adapting to their temporality	*Well they would understand that for example, if I need to sit down sometimes or if I'm walking with them they will slow down* *they won't mind or make a big deal, they would just make it part of the trip, of the journey, you know, they just take my pain as sort of part of me somehow and we go along with it and they don't make a fuss out of it, they don't make it like... they acknowledge it but they don't make a fuss out of it, which is quite* *I know I have to deal with it. It's true maybe I suppose and they understand if I need to sit down, they would sit down and we carry on talking, it doesn't interfere really in our rapport.* *the fact is that obviously I was frustrating others as well, so it was quite, it was a difficult situation to be in because they were waiting for me, to get better to go on holidays* *If I'm in pain one day is alright, the second day becomes really…the third day you know…"when is it going to go away!" so it's like… there's a certain element that after a while, they can't take it anymore* *I mean, if I'm walking with other people they have to understand that I can't walk that fast*
Theme 5 - Clinicians approach pain from a reductive perspective which has an impact on the diagnosis	*sometimes when the pain is so painful you don't really know where…* *that's my general concern about the NHS, is that they don't treat you as a whole, they treat little individual pain* *someone could have given me that diagnosis long time ago but they've been wasting a lot of time I think.* *Yes I saw some rheumatologist and I've been seeing different sort of, different specialists from different hospitals* *from the hospital point of view they were all saying "is degenerative"*
Theme 6 - The possibility of finding meaning in the experience of pain	*but you know any pain brings you more towards death to a certain degree that's how I view it* *Yes, it feels alienated but at the same time you realise, how many people got the same problem, so you can be closer to this people too, you can engage, you can realise that you are not the only one,* *there is some emotional element probably within as well…*
Theme 7 - Others react to pain from a doing mode	*I think nobody really like seeing someone else in pain,* *but I think in general people don't know what to say, they want the pain to go away, they will give you pain killers, or they would give you something to make it vanish, or go and see this doctor*

Other	*it stopped me from going on holidays and it stopped me from really working properly* *But at work I find it difficult. I mean at work I am supposed to do lots of things so I can't really show that I'm in much pain* *…. yeah I want to feel that I'm still efficient, they are not going to sack me, I don't feel that at all, I just feel I want to be on top of it, I want to be able to do the things that I am supposed to do rather than feeling...*
THIRD READING THEMES	**THIRD READING - Interpretative Statements**
Theme I - OTHERS KNOW MORE ABOUT MY PAIN	The ultimate aim was to get a diagnosis Pain can be explained by others I suffer from a diagnosis It's always different but always degeneration. There is an idea of definite answer Constantly been told what to do by other people/ Pain is treated differently in different places Other people can help with pain, supposedly I do what others say, not sure it works Medics know why I am in pain Medics have more information than me about my pain and they don't always share it Shows that alternative doctors can give alternative explanations For doctors inflammation and degeneration is fine, like having nothing Pain is normal in some cases Degenerative pain is not concerning When treating pain, there is something one can do but in a context that it is dictated by others Medical professionals assume pain, expect pain Shows that for doctors, it is possible to be in pain and have nothing
Theme II - When in pain, life stops. Life ceases to be	Pain gets upsetting when one is incapable of doing things Normal things cannot be done with pain Pain is expressed in the not doing Pain is expressed in cessation, there is no need for words, pain can be observe in the stopping in the pause Pain brings things to a halt and that is a source of worry Pain stops me Pain restricts Pain makes us feel stuck When in pain I'm stuck but not still When getting stuck with pain, I get stuck in my being for the others

Theme III - It is possible to make meaning out of the experience of chronic pain	It's better to be in pain and have legs and be able to move Shows that the pain has a meaning, is a form of symbol. Looking for the symbolic aspect of the pain experience I can still humour the fact that I am in pain It's better to be in pain and have legs and be able to move Adjusting to life means finding meaning in a world where the body does not play an important role It is possible to adapt to pain, to a certain degree Pain is an experience that may make us want to reassess our lives, give it a new meaning Shows that pain involves a form of loss of the body as a vehicle to do things we love such as our jobs but that loss can be overcome Shows the idea that pain is a reminder of our limitations and our death The resistance to talk about pain can be overcome by making this a purposeful task The only purpose of talking about pain has to do with finding a meaning There is a feeling of belonging when pain is understood as a human experience, something that we will all eventually experience at some point in our lives When in pain, there is also an element of choice, I cannot fight the pain but I can still exercise certain control and choose what to do to feel better. I can manage, I have to find the way
Theme IV - pain alters temporality, life happens at a different pace	Pain implies a sense of temporality, slows down, pauses Pain brings a temporality that is different to others, pain is intermittent The nature of pain is often elusive in its temporality and spatiality Pain prevents you from committing

Theme V - When in pain, I cannot be for others, I fail them	When in pain, I cannot be for others, I fail them Being in pain prevents me from being with others When in pain, is better to be with oneself Shows that pain restricts but I cannot be fully for the other so I have to choose Having to retreat due to pain affects others Others get annoyed with my being in pain Others get annoyed because pain prevents them from getting something from me Shows that when in pain it is hard to turn to others and being with and for others fully When getting stuck with pain, I get stuck in my being for the others There is an idea of failing others when in pain The discomfort that pain creates disturbs other people People in pain can perceive other's reactions and these are not positive Pain interrupts my relationship with the world and also interrupt the relationship of others with their own world If I show I'm in pain, I become less reliable. Someone who shows pain can't be considered efficient My pain generates anger in others Others experience anger when I am in pain because I cannot do my part, my pain makes other's life difficult My pain impinges on other people Even if we can get over the loss of the body as such, the worst is how pain makes us fail to others Shows that pain prevents me from being fully with others Pain prevents engaging with others who need me When in pain I cannot be there for those who need me, who rely on me, pain affects my role of a carer, a mother, partner Pain makes you go inwards, concentration is put on the subject and there is not room for intersubjectivity, no concentration, no energy Pain makes you disconnects with others but make you feel connected to others in pain too There is a way for others to be with pain, being instead of doing It is possible to laugh with other about the pain Normal commitments can be an ordeal when in pain People can tell others that they suffer from pain, but when in pain, they hide Reactions to pain can be kindness but with elements of irritation Shows that there is a some tolerance threshold when it comes to be with someone in pain People don't want to see others in pain
Theme VI - PAIN means having to live with caution	Pain brings caution There is an anxiety about the vulnerability that pain can create, adventure is risk. Pain cuts the link with the other, which is sad Close people can be supportive when one is in pain But pain does create irritation It does not feel well when others don't understand how bad the pain is Not feel well when others don't understand how bad the pain is

Theme VII - PAIN is dynamic and systemic and cannot be reduced	Shows that pain cannot always be restricted to one area, but others think this is the case Pain experience cannot be explained through a chart When pain is being addressed by medical professionals is not treated as a whole experience but as a localised event Parts vs the whole when treating pain
Theme VIII - Living with pain is living with uncertainty	Shows the uncertainty about pain, not always knowing what the triggers are. The uncertainty and unpredictability are among the most problematic aspects of pain You don't know what to expect when you are in pain Pain can come at any time, any moment, the idea of pain looming over There is the uncertainty about when pain is going to show up and the uncertainty about how it will develop from the onset
Theme IX - There is a way for others to be with pain, being instead of doing	It is possible to laugh with other about the pain Some people can take the pain more than others, pain can be understood Shows that the way of being with someone in pain is by attacking the pain Others are interested in pain when it comes to fight it but not reflect on the experience It makes a difference when people help me with my pain in different ways, such as touching It shows that others understand pain when they adjust to the person in pain needs I feel understood when others take me with my pain, they acknowledge and they accommodate without it being a big issue When others adjust, pain does not interfere in the relation Shows that people can relate differently to pain, pain can be understood without making too many questions

Appendix 8 – Configuration of the themes

Part 1 – List of themes

1 - Accepting and adapting to a life with pain

2 - I can't be for others when I'm in pain. Pain demands my full attention

3 - Uncertainty about the body's response create a sense of lack of control

4 - Being with other in pain means adapting to their temporality

5 - Clinicians approach pain from a reductive perspective which has an impact on the diagnosis

6 - The possibility of finding meaning in the experience of pain

7 - Others react to pain from a doing mode

1 - others know more about my pain

2 - when in pain, life stops. Life ceases to be

3 - it is possible to make meaning out of the experience of chronic pain

4 - pain alters temporality, life happens at a different pace

5 - when in pain, i cannot be for others, i fail them

6 - pain means having to live with caution

7 - pain is dynamic and systemic and cannot be reduced

8 - living with pain is living with uncertainty

9 - there is a way for others to be with pain, being instead of doing

1- Just because I am coping/looking good it does not mean I am not in pain (Invisibility?)

2 – negative medical encounters: lack of context, reductive, not understanding

3 - Hostage of pain no longer able to interact with the world

4 - People who suffer from the same condition are able to understand what is like to live with pain

5 – new relationship with time and space and dissonance with others

6- body in pain is no use to others

7- Pain is an interruption, feeling self-conscious of this

8- There is a new identity, no longer recognised by her or others – sense of loss

9- being a woman has different implications to the experience of pain

1 – I have no control over my pain, I can only manage

2 - pain makes me unavailable to others

3 - need to go slow, moving in a different space-time dimension that others do not understand

4 - being a woman adds complexity to the experience we have with our bodies and how others see our bodies.

5 - pain is invisible, people assume i am doing well because i look well

6 the medical gaze fails to understand the full experience of pain

7 - Trying to find the meaning of this pain

1 - Cut off from relational world

2 - Stuck in pain which is both a physical and emotional experience

3 - The diagnosis and the power of the medical gaze

4 - Pain is invisible – need to convince others that she is not crazy and that she has a disability

5 - Feeling constantly judged for my pain and dismissed of my experience

6 - Relating with the world is moderated by the experience of pain

7 - When there is understanding – when others accept the pace and give time"

1 - Pain is omnipresent and omnipotent

2 - Diagnosis has been an ordeal and a relief

3- Physical pain is emotional pain

4- Can't have both pain and others in my life. I can no longer be part of the society

5 - I feel like I need to prove my illness to others. My experience of pain is dismissed and denied

6 - When others understand

7- New relationship with time and space

1 - my pain has been dismissed over and over again

2 – I feel let down by the NHS,

3 – pain (and treating pain) has taken over my life

4 – I need to accept that pain will always be in my life and i need help to manage it but living in constant pain is depressing

5 – there is something wrong but we can't see it – I want a diagnosis

6 – others don't understand and don't empathise

7 – women's pain is not taken seriously

1 - Treated seriously means been heard and a commitment to action

2 - Feeling abandoned and hopelessness, falling into despair

3 - It's all about time: the long wait, the short encounter

4 - Raising from despair: the need to accept and take responsibility

5 - Medication: the lesser of two evils

6 - Pain is omnipresent and omnipotent – pain also threatens my future

7 - The only relationship I have is with pain

8 - Diagnosis – there is something wrong. There is nothing physical, your diagnosis is pain.

9 - Women's health is undervalued

10 - Pain is a threat but not urgent (experience of pain as being urgent but not treated like it is)

11 - there is help, I just need to pay for it

12 - On feeling understood – nobody can understand what my pain feels like but they can understand the impact it has on my life.

13 - Normality and dismissal

1 - Not one pain but many and the medical gaze cannot see the whole but only the parts

2 – Pain is omnipotent and omnipresent but also unpredictable

3 - The loss for the life she had and the life she could have

4 - Pain medication is not enough and I need more but this is not been given to me

5 - Doctors do not listen what I have to say about my pain and how it is affecting my life

6 - I have realised that I will not receive the help I need, therefore I must accept this and take responsibility for my own health

7 - My pain is invisible, people cannot understand and cannot respond to my pain

8 - I have to push myself to do what I want/need but the pain after is worse

1 - Pain is everywhere, relentless and unpredictable

2 - Medical encounters are devoid of meaning

3 - Pain gets lost in the medical power dynamics

4 - Pain is treated based on the doctors' preconceived assumptions

5 - In spite of wanting it, a diagnosis can have a negative impact on pain treatment

6 - Pain medication – the side effects and risks

7 – Negotiating with pain and despair; reaching acceptance

8 – Pain is a barrier to relate and leads to isolation

9 – others cannot see my pain and my suffering

10 – the price I pay for being with others is more pain

11 – I have been let down by the medical system, I need to take responsibility for my own health

12 – I am in a body that does not belong to me

13 – I need adjustments and flexibility in order to engage with the world

1 – Pain is everywhere and all the time

2 – Diagnosing fibromyalgia takes time and can be seen as an imagined illness

3 – The psychological impact of chronic pain is as bad as the pain itself and it's a lonely journey

4 – My pain is invisible, others cannot understand my suffering

5 – Pain controls my present and my future. Pain is unpredictable and so am i

6 – Wanting to feel listened to but not wanting to be seen as a complainer

7 – Women's health is more complex and pain has a different impact on them

1 - A diagnosis is felt as a relief but does not necessarily provide a meaningful explanation to the symptoms

2 - Relationship with pain feels alien, pain has a its own self

3 - Pain is everywhere and always there

4 - Pain is uncertainty

5 - In the absence of physical evidence, pain remains invisible. It does not belong to the realm of the body but of the mind instead

6 - It's hard to feel listened too. Nobody wants to hear about suffering but it's also difficult to show that I am suffering

7 - The way I relate to my pain affects the way I relate to others, who fail to understand my suffering

8 - Pain has shaped the way one relates to the possibility of motherhood

9 - Pain and anxiety are interrelated phenomena

1 - Pain is a constant, being in pain is normality and so is being stuck

2 - Feeling that clinicians could listen more and show more curiosity instead of quickly dismissing or diagnosing

3 - Feeling tired of the same narrative and the lack of understanding. Pain needs to be explained to others

4 - Living with chronic pain has a profound impact on identity. Hard to reconcile the perceived identity with the physical identify and the limitations imposed by pain

5 - Pain prevents me from relating with others. Impossibility of being in both places at one, it's either pain or the other.

6 – Pain prevents from planning

1 – Pain is omnipresent and its presence is normality

2 – Encounters with clinicians are devoid of active listening and openness

3 – Chronic pain is complex, diagnoses are descriptive and treatments palliative

4 - Talking about pain with friends feels pointless and may trigger shame

5 – Whilst being in pain, it is impossible to give oneself to another, creating feelings of being a burden and a disappointment

6 – For those who suffer from chronic pain, the future is blurry and scary too

7 – Constant negotiation and acceptance between what the mind wants and what the body can do.

1 -I need my medication and that it's not been given to me. I am treated like an addict

2 - I need to take desperate measures in order to be heard by the clinicians

3 - Not getting the help she needs from clinicians, provide neither the treatment nor the answers

4 - Not feeling listened to, talking therapies is not the answer. The listening needs to come from the clinician first

5 - The pain separated me from what I want to do

6 - Pain feels indescribable, therefore difficult to understand by others

7 - Pain has made me lose my independence

1 - Feeling let-down by the healthcare system, not feeling listened too, not attending to the individual experience

2 - Feeling powerless when it comes to the decisions about medication

3 - Despair and helplessness calls for desperate measures in order to receive help

4 - Pain brings life into a halt, withdrawal from the world

5 - Chronic pain leads to the creation of a new identity where time is experienced differently

6 - Lack of medical evidence and referral to psychological services, makes Fibromyalgia is a disputable diagnosis

7 - When talking about pain, others can be rejecting and judgemental but those with health issues can be more able to understand

Part 2 - Group categories

Rising above despair and coming to a place of acceptance

(R) Theme 1 - Accepting and adapting to a life with pain

(D) Theme 4 – I need to accept that pain will always be in my life and i need help to manage it but living in constant pain is depressing

(D) Theme IV- raising from despair: the need to accept and take responsibility

(T) Theme 6 - I have realised that I will not receive the help I need, therefore I must accept this and take responsibility for my own health

(T) Theme VII– negotiating with pain and despair; reaching acceptance

Pain demands full attention and there is no room for others

(R) Theme V- when in pain, I cannot be for others, I fail them

(R) Theme 2 - I can't be for others when I'm in pain. Pain demands my full attention

(E) Theme 6 - body in pain is no use to others

(E) Theme 8 -There is a new identity, no longer recognised by her or others – sense of loss

(E) Theme II - pain makes me unavailable to others

(M) Theme 1 - Cut off from relational world

(T) Theme VIII – pain is a barrier to relate and leads to isolation

(T) Theme X – the price I pay for being with others is more pain

(N) Theme VII- The way I relate to my pain affects the way I relate to others, who fail to understand my suffering

(N) Theme VIII- Pain has shaped the way one relates to the possibility motherhood

(J) Theme 5 - Pain prevents me from relating with others. Impossibility of being in both places at one, it's either pain or the other.

(J) Theme V– Whilst being in pain, it is impossible to give oneself to another, creating feelings of being a burden and a disappointment

(M) Theme IV- Can't have both pain and others in my life. I can no longer be part of the society

(D) Theme VII- the only relationship I have is with pain

Pain is unpredictable therefore life is uncertainty

(R) Theme 3 - Uncertainty about the body's response create a sense of lack of control (uncertainty/future)

(R) Theme VI - pain means having to live with caution

(E) Theme I – I have no control over my pain, I can only manage

(N) Theme IV- Pain is uncertainty

(J) Theme 6 – Pain prevents from planning

(J) Theme VI – For those who suffer from chronic pain, the future is blurry and scary too (future/uncertainty)

(R) Theme VIII - living with pain is living with uncertainty

When in pain, time and space are experienced differently

(R) Theme 4 - Being with other in pain means adapting to their temporality

(R) Theme IV- pain alters temporality, life happens at a different pace

(E) Theme 5 – new relationship with time and space and dissonance with others

(E) Theme III - need to go slow, moving in a different space-time dimension that others do not understand

(M) Theme 7 - When there is understanding – when others accept the pace and give time

(M) Theme VII- New relationship with time and space

(T) Theme XIII – I need adjustments and flexibility in order to engage with the world

(V) Theme V- Chronic pain leads to the creation of a new identity where time is experienced differently (x2)

Feeling hostage to pain

(R) Theme II - when in pain, life stops. Life ceases to be

(E) Theme 3 - Hostage of pain no longer able to interact with the world

(E) Theme 7 - Pain is an interruption, feeling self-conscious of this

(V) Theme 5 - The pain separated me from what I want to do

(V) Theme IV- Pain brings life into a halt, withdrawal from the world

(M) Theme 2 - Stuck in pain which is both a physical and emotional experience (x2)

(J) Theme 1 - Pain is a constant, being in pain is normality and so is being stuck

Clinicians do not listen, encounters with them are meaningless

(D) Theme I - treated seriously means been heard and a commitment to action

(D) Theme III - it's all about time: the long wait, the short encounter (being listened to)

(T) Theme 5 - doctors do not listen what I have to say about my pain and how it is affecting my life

(T) Theme II - medical encounters are devoid of meaning

(N) Theme 6 – Wanting to feel listened to but not wanting to be seen as a complainer

(J) Theme 2 - Feeling that clinicians could listen more and show more curiosity instead of quickly dismissing or diagnosing

(J) Theme II – Encounters with clinicians are devoid of active listening and openness

(V) Theme 4 - Not feeling listened to, talking therapies is not the answer. The listening needs to come from the clinician first

(V) Theme 2 - I need to take desperate measures in order to be heard by the clinicians

Other people cannot understand what living with pain feels like because they do not suffer from it

(D) Theme 6 – others don't understand and don't empathise

(R) Theme 7 - Others react to pain from a doing mode

(D) Theme XII - on feeling understood – nobody can understand what my pain feels like but they can understand the impact it has on my life.

(N) Theme VI - It's hard to feel listened too. Nobody wants to hear about suffering but it's also difficult to show that I am suffering

(J) Theme 3 - Feeling tired of the same narrative and the lack of understanding. Pain needs to be explained to others

(J) Theme IV- Talking about pain with friends feels pointless and may trigger shame

(V) Theme 6 - Pain feels indescribable, therefore difficult to understand by others

(V) Theme VII - When talking about pain, others can be rejecting and judgemental but those with health issues can be more able to understand

Subtheme 1 – People who experience pain are more able to understand and empathise.

(E) Theme 4 - People who suffer from the same condition are able to understand what is like to live with pain

Subtheme 2 – Others can be with pain

(M) Theme VI - When others understand, adjust and make room for her differences

(R) Theme IX- there is a way for others to be with pain, being instead of doing

Pain is omnipresent and omnipotent

(M) Theme 6 - Relating with the world is moderated by the experience of pain

(M) Theme I - Pain is omnipresent and omnipotent

(D) Theme 3 – pain (and treating pain) has taken over my life

(D) Theme VI - pain is omnipresent and omnipotent – pain also threatens my future

(T) Theme 2 – pain is omnipotent and omnipresent but also unpredictable

(T) Theme I - pain is everywhere, relentless and unpredictable

(N) Theme 1 – Pain is everywhere and all the time

(N) Theme 5 – Pain controls my present and my future. Pain is unpredictable and so am I

(N) Theme II - Relationship with pain feels alien, pain has a its own self

(N) Theme III - Pain is everywhere and always there

(J) Theme I – Pain is omnipresent and its presence is normality

Pain is seen from a medical reductionist and fragmented gaze

(R) Theme VII- pain is dynamic and systemic and cannot be reduced

(E) Theme 2 – negative medical encounters: lack of context, reductive, not understanding

(R) Theme 5 - Clinicians approach pain from a reductive perspective which has an impact on the diagnosis

(E) Theme VI - the medical gaze fails to understand the full experience of pain (reductionist)

(T) Theme 1 - not one pain but many and the medical gaze cannot see the whole but only the parts (reductive)

In spite of searching for a diagnosis, having one does not necessarily provide more relief

(M) Theme II - Diagnosis has been an ordeal and a relief

(D) Theme 5 – there is something wrong but we can’t see it – I want a diagnosis

(D) Theme VIII- diagnosis – there is something wrong. There is nothing physical, your diagnosis is pain.

(T) Theme V - in spite of wanting it, a diagnosis can have a negative impact on pain treatment

(N) Theme 2 – Diagnosing fibromyalgia takes time and can be seen as an imagined illness

(N) Theme I - A diagnosis is felt as a relief but does not necessarily provide a meaningful explanation to the symptoms

(J) Theme III – Chronic pain is complex, diagnoses are descriptive and treatments palliative

(V) Theme VI - Lack of medical evidence and referral to psychological services, makes Fibromyalgia a disputable diagnosis

Physical pain is emotional pain

(M) Theme 2 - Stuck in pain which is both a physical and emotional experience (x2)

(N) Theme 3 – The psychological impact of chronic pain is as bad as the pain itself and it’s a lonely journey

(M) Theme III- Physical pain is emotional pain

(N) Theme IX - Pain and anxiety are interrelated phenomena

Feeling let down by the medical system

(D) Theme 2 – I feel let down by the NHS,

(T) Theme XI – I have been let down by the medical system, I need to take responsibility for my own health

(V) Theme 3 - Not getting the help she needs from clinicians, provide neither the treatment nor the answers

(V) Theme I - Feeling let-down by the healthcare system, not feeling listened too, not attending to the individual experience

(D) Theme II - feeling abandoned and hopelessness, falling into despair (let down)

Pain is invisible to others and so is the suffering associate to it

(T) Theme 7 - my pain is invisible, people cannot understand and cannot respond to my pain

(T) Theme IX– others cannot see my pain and my suffering (invisibility)

(N) Theme 4 – My pain is invisible, others cannot understand my suffering

(N) Theme V- In the absence of physical evidence, pain remains invisible. It does not belong to the realm of the body but of the mind instead

(M) Theme 4 - Pain is invisible – need to convince others that she is not crazy and that she has a disability

(E) Theme 1 –just because I am coping/looking good it does not mean I am not in pain (Invisibility?)

(E) Theme V - pain is invisible, people assume I am doing well because I look well

The experience of pain is constantly dismissed by others and there is a need to prove that what they experience is real and intolerable

(D) Theme X - pain is a threat but not urgent (experience of pain as being urgent but not treated like it is) (dismissal)

(D) Theme XIII - normality and dismissal (power?)

(M) Theme 5 - Feeling constantly judged for my pain and dismissed of my experience

(M) Theme V - I feel like I need to prove my illness to others. My experience of pain is dismissed and denied

(D) Theme 1 - my pain has been dismissed over and over again

The complexity of women's body needs to be taken into account when dealing with chronic pain

(D) Theme 7 – women's pain is not taken seriously

(D) Theme IX- women's health is undervalued

(N) Theme 7 – Women's health is more complex and pain has a different impact on them

(E) Theme IV- being a woman adds complexity to the experience we have with our bodies and how others see our bodies.

(E) Theme 9 - being a woman has different implications to the experience of pain

Feelings of powerlessness describe the relationship between patient and clinician in the treatment of pain.

(R) Theme I - others (clinicians) know more about my pain (power)

(M) Theme 3 - The diagnosis and the power of the medical gaze (power)

(T) Theme III - pain gets lost in the medical power dynamics

(T) Theme IV- pain is treated based on the doctors preconceived assumptions (power)

(V) Theme II - Feeling powerless when it comes to the decisions about medication (power)

Losing identity through pain and the feelings of loss

(T) Theme XII – I am in a body that does not belong to me (identity)

(J) Theme 4 - Living with chronic pain has a profound impact on identity. Hard to reconcile the perceived identity with the physical identify and the limitations imposed by pain

(J) Theme VII– Constant negotiation and acceptance between what the mind wants and what the body can do.

(V) Theme V- Chronic pain leads to the creation of a new identity where time is experienced differently (x2)

(V) Theme 7 - Pain has made me lose my independence

(T) Theme 3 - the loss for the life she had and the life she could have (identity)

(E) Theme 8 -There is a new identity, no longer recognised by her or others – sense of loss (repeat)

Medication; navigating between the risks of addiction and side effects

(D) Theme V- medication: the lesser of two evils

(T) Theme VI - pain medication – the side effects and risks

(V) Theme 1 -I need my medication and that it's not been given to me. I am treated like an addict

(T) Theme 4 - pain medication is not enough and I need more but this is not been given to me

Chronic pain is a meaning making opportunity

(R) Theme 6 - The possibility of finding meaning in the experience of pain

(R) Theme III - it is possible to make meaning out of the experience of chronic pain

(E) Theme VII - Trying to find the meaning of this pain

Other

(V) Theme III - Despair and helplessness calls for desperate measures in order to receive help

(T) Theme 8 - I have to push myself to do what I want/need but the pain after is worse

(D) Theme XI - there is help, I just need to pay for it

Part 3 – Generating general themes

1. **Rising above despair and coming to a place of acceptance**
2. **Pain demands full attention and there is no room for others**
3. **Pain is unpredictable therefore life is uncertainty**
4. **When in pain, time and space are experienced differently**
5. **Feeling hostage to pain**
6. **Clinicians do not listen, encounters with them are meaningless**
7. Other people cannot understand what living with pain feels like because they do not suffer from it
8. **Pain is omnipresent and omnipotent**
9. **Pain is seen from a medical reductionist and fragmented gaze**
10. **In spite of searching for a diagnosis, having one does not necessarily provide more relief**
11. **Physical pain is emotional pain**
12. **Feeling let down by the medical system**
13. **Pain is invisible to others and so is the suffering associate to it**
14. **The experience of pain is constantly dismissed by others and there is a need to prove that what they experience is real and intolerable**
15. **The complexity of women's body needs to be taken into account when dealing with chronic pain**
16. **Feelings of powerlessness describe the relationship between patient and clinician in the treatment of pain.**
17. **Losing identity through pain and the feelings of loss**
18. **Medication; navigating between the risks of addiction and side effects**
19. **Chronic pain is a meaning making opportunity**

- **Theme 1 – “I cannot”: pain and the arrested self**

Pain demands full attention and there is no room for others
Pain is unpredictable therefore life is uncertainty
When in pain, time and space are experienced differently
Feeling hostage to pain
Pain is omnipresent and omnipotent

Omnipotent
Omnipresent
Unpredictable
Going slow

- **Theme 2 – "I am not": the lost self and meaning-making**

Rising above despair and coming to a place of acceptance
Physical pain is emotional pain

Losing identity through pain and the feelings of loss
Chronic pain is a meaning making opportunity

Loss of identity
Emotional pain
Meaning
Agency/acceptance

- **Theme 3 – “This is real": the need to be legitimised**

Clinicians do not listen, encounters with them are meaningless
Other people cannot understand what living with pain feels like because they do not suffer from it
Pain is seen from a medical reductionist and fragmented gaze
Feeling let down by the medical system
Pain is invisible to others and so is the suffering associate to it
The experience of pain is constantly dismissed by others and there is a need to prove that what they experience is real and intolerable
The complexity of women’s body needs to be taken into account when dealing with chronic pain
Feelings of powerlessness describe the relationship between patient and clinician in the treatment of pain.
Medication; navigating between the risks of addiction and side effects
In spite of searching for a diagnosis, having one does not necessarily provide more relief

Invisible
Not heard
Powerlessness
Let down/lack of knowledge