Kaleidoscope of Pain: What and How Do You See Through It

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> Context · Among the many theories of pain, the biopsychosocial explanation of pain remains the most established in medicine. However, the three components are unevenly represented, with emphasis on the biological component. From this perspective the experience of pain may considered as an epiphenomenon. > **Problem** • I empirically investigated the characteristics of pain (especially chronic pain) and investigated how these characteristics relate to existing conceptualizations of pain. > Method • A case-study approach was used to demonstrate different ways of understanding and describing pain. Case-study data were collected by two co-researchers through a series of clinical and research-focused phenomenological interviews with eleven people experiencing chronic pain. The aim of the analysis was to explore and evaluate empirical support for the 5E theory of pain. > Results • The findings point to the insufficiency of the biopsychosocial approach to understanding pain and support a qualitatively different approach to its investigation. The enactivist and phenomenological approach, and the "horizons of attending to experience," may open new perspectives on pain perception. > Implications · Enactivism and phenomenology offer important theoretical advancements. A shift away from biological or biologically oriented approaches (e.g., biomedical and biopsychosocial models) is necessary to better understand the complexity of first-person experience of chronic pain. The shift is needed because of the complex and overwhelming nature of (chronic) pain, which cannot be described by (any) three components. However, understanding the process of constant interaction between somebody in pain and herself, and with her environment, meaning understanding the dynamic of how pain is embodied, embedded, enacted, extended and emotive, can bring a new level of understanding of pain and patients who suffer. "Horizons of attending to experience" are an additional offering for the holistic approach to understanding patients in pain, and to facilitate better coping. > Constructivist content • When studying phenomena of consciousness such as pain, an enactivist and phenomenological approach should be considered, consistent with the constructivist approach. > Key words • 5E, chronic pain, enaction, first-person research, horizon of attending to experience, subject-object integration.

Introduction

«1» Pain is a very specific phenomenon, one of the oldest conditions known to humankind that causes distress, thus an extraordinary number of theories have been developed to understand it, and many researchers have conducted various studies, and many groups of scientists and doctors (e.g., an International Association for the Study of Pain - IASP) have tried to define it from the practical point of view. However, we still do not have an understanding (and consequently a definition) of pain that would unite these numerous ideas about pain so that we could fully grasp it; this applies even more to chronic pain. Many medical treatments exist (e.g., pharmaceutical, surgical, neuro-augmentative, somatic, behavioral, rehabilitative, complementary and alternative treatment) but they are, especially for chronic pain, mostly inefficient

in reducing the unpleasant physiological experience of (chronic) pain and suffering, and improving functionality and the quality of life of patients (Turk, Wilson & Cahana 2011). In some treatments, such as opioid treatment, patients' quality of life and health get even worse in the longer term. Probably, this inability to understand and provide efficient treatment is also because of the variety of forms of pain, such as acute and chronic pain, nociceptive, neuropathic pain, peripheral and central pain.

« 2 » In this article, I look through a kaleidoscope of different approaches to the study of pain, with the purpose of gathering different possible understandings of pain and proposing a modus operandi that is congruent with constructivists' theory of 4E and (also experimental) phenomenology of pain. Although some may not see a clear connection between the constructivist and phenomenological approaches, there are quite a

few. At the most basic level, both approaches are concerned with subjective experience, the primacy of experience, and its structures (Rasmussen 1998). Further, for both, meaning is created through experiences in the world, as well as the connection between the knower and the known (Seigfried 1976). In other words, our realities are constructed through participatory, active contributions by the agent/knower who constructs their reality through personal participatory, active contributions within a social framework. Importantly, this requires a world that is given meaning and structure through the operations of consciousness. At this point, the connection between constructivism and phenomenology is, arguably, the strongest and the clearest: even as constitutable, the world still requires a person's capacity for phenomenological constitution. That is, as an epistemological and experiential structure, consciousness ultimately involves that

individuals link through a shared conscious connection in which we find the intersubjective or social construction taking place (Schutz 1972). The process of knowledge acquisition connects both, constructivism and phenomenology: the phenomenological approach is premised on a descriptive process and, after it unfolds, the resulting insight can be explored by means of constructivism.

«3» In the first part of the article, I provide a brief overview of the different theories of pain in order to explore what has already been observed about pain, since the historical overview can also highlight current understanding and its advantages and shortcomings. I particularly emphasize the enactivist and phenomenological approaches, as clinical experience underscores the need to explore patients' experiences in order to diagnose pain and understand the pain experience. For the experimental part, I focus on chronic pain since it seems the most complex and the most life-changing form of pain. I present findings from a study that aimed to explore different experiences of chronic non-cancer pain (described as moderate or severe pain that lasts for six or more months and is attributed to conditions such as neuropathic pain, rheumatoid arthritis, lower back pain, osteoarthritis, fibromyalgia and a range of several other conditions; Gupta & Atcheson 2013) from a first-person perspective. The results are combined with discussion, as is often the case in qualitative studies.

Pain as a biomedical phenomenon

"4" I begin the presentation of approaches with the biomedical model of pain perception that is historically the oldest and still the most prominent in clinical circles. It mainly consists of theories explaining specificity (specialized nerves), intensity (pain occurring in any sensory system when sufficient intensity is reached), pattern (specific patterns of neural activity), and some initial ideas about connection/ distinction between some physical and psychological aspects of pain (e.g., gate control, emphasizing that the transmission of pain to the brain can be blocked, Moayedi & Davis 2012).

René Descartes (1972) was one of the first in the West who described a detailed somatosensory pathway, but he also distinguished between sensory transduction of pain and the perceptual experience of it. Many followed his trail of thought (e.g., Charles Bonnet, John Hunter, Albrecht von Haller) and some improved physiological knowledge of pain and sensory pathways (e.g., Charles Bell, Magnus Gustaf Blix, Alfred Goldscheider).

«5» From here physiological theories are divided into three streams: specificity theories, intensity theories and pattern theories and later develop to the biomedical model that understands body as a biological organism, which, when in pain, is out of order, which can be detected medically (e.g., imaging techniques, blood tests). With the development of neuroscience, this notion became even more dominant and reinforced with three widespread models of pain: inflammatory pain, neuropathic pain and cancer pain, which have fostered the discovery of important clinical treatments (e.g., new analgesic agents). Genetics and molecular biology additionally promoted the biomedical view of pain, as genes can influence neuronal activity involved in pain transmission (Gatchel et al. 2007).

« 6 » In addition to the above theories, there are many others included in this approach, but they all see experience of pain mostly as an epiphenomenon, a consequence of tissue damage, a secondary symptom of lesser importance. They also claim pain intensity corresponds to the extent of tissue damage (Gatchel et al. 2007), and even if their description of the nociceptive system is appropriate, it does not sufficiently cover the complexity of the pain system and experience, in particular of those in chronic pain (Moayedi & Davis 2012).

Pain as a biopsychosocial phenomenon

«7» The second main approach, also spreading from ancient to modern times, is the biopsychosocial approach. In modern time, William Livingston (1943) was first to describe pain as a dynamic interweaving of sensory experience and subjective, individual perception and emotion (Melzack &

Wall 2003). Ronald Melzak's work, first in collaboration with Patrick Wall on the gate control theory (Melzack & Wall 1965) and later with Kenneth Casey on the neuromatrix theory (Melzack & Casey 1968), and separately the work of George Engel (1977) were instrumental in overcoming the biological conception of pain. They all added a subjective and emotional dimension to pain perception, and prompted thinking resembling a modern definition from IASP and a modern biopsychosocial model of pain. This defines pain as: "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage," and is contextualized by additional notes and the etymology of the word pain. Through this, personal experience of pain is emphasized and (experience of) pain is differentiated from nociception (Raja et al. 2020).

«8» Nowadays psychological and socio-environmental aspects of pain are added to the biological view, in an attempt to unite them under one roof. This approach, however, when applied in practice, usually divides individuals' pain into two (biological and psychosocial) or three (biological, psychological and social) components (Mescouto et al. 2020). Thus, it does not genuinely combine these components, it just adds one to the other, and most importantly, it still prioritizes the biological component. This is also observed in the IASP definition of pain - although its accompanying notes accept the importance of subjectivity in the experience of pain, they also understand it as a phenomenon mostly based on the activity of sensory neurons. Something similar might be said about the onion model (Loeser 1980, 2006) that builds on nociception but adheres also to cognitive, affective, and behavioral factors as well as past experiences. However, even though it considers suffering as generated by psychological states, it regards it as originating solely from the brain. John Loeser's contribution is also a qualitative distinction between acute pain (as a symptom) and chronic pain (as a disease), and recognizing pain as a "personal, internal event that can never be known by an external observer" (Loeser 2006: 14), which by itself, invites a phenomenological thinking and research approach.

« 9 » There have been other attempts to change the hierarchy of these components to emphasize either psychological factors, such as the fear-avoidance model (Vlaeyen & Linton 2000), or sociological factors, such as the social-communication model of pain (Craig 2009). There has also been an attempt to explain how cognition (e.g., content and persistence of thoughts) can alter the perception of a sensory stimulus that may trigger pain (Moseley & Butler 2015). These attempts have sought to give greater weight to emotions such as anxiety, depression, anger, fear, and cognitive processes, such as catastrophizing the experience of pain (Gatchel et al. 2007). However, the field of general pain management did not give these attempts much recognition.

« 10 » A review of current pain theories and models shows that all recognize the importance of biological/physiological factors, and most also acknowledge the relevance of some other factors such as emotional, cognitive and social/cultural, but they include different factors and have unique views about their contribution to pain perception. However, perhaps a shift in perspective is needed in clinical practice, as much more can be done to consider non-physiological factors to help clients more and give them more options and a voice. When looking at and examining a human condition like pain in its individual manifestations, different foci emerge like different colored patterns in a kaleidoscope.

Pain and 5E

« 11 » The enactive approach emphasizes the body as being crucial for cognition, selfindividuation, agency, and (social) interaction with the world (Di Paolo, Buhrmann & Barandiaran 2017). The approach, as a basis for the study of pain, is a logical continuation of previous theories, however, it is more dynamic and comprehensive. Embodied experience of pain is unarguable, but the meaning of it stays clouded. As the enactive approach generally builds on phenomenology (e.g., Maurice Merleau-Ponty's phenomenology of the lived body) and cognitive science, incorporating theories of perception (e.g., embodied cognition, predictions of the world through brain-body-environment interaction) and building on notions of autopoiesis and structural coupling, the enactive approach to pain also embraces the same building blocks. In this section, I will recapitulate the main dimensions of the enactivist approach to cognition and show for each what it can contribute to understanding pain, in congruence with Peter Stilwell and Katherine Harman (2019). Although there are some critics, mainly from cognitivists, of this concept, there is also much support for it (Menary 2010). As a consistent and valid response to the neurocentric approach to cognition, 4E cognition: embodied, embedded, enacted, and extended has become widely accepted in research in many areas of life, e.g., memory, language, psychopathology, psychotherapy, skill performance, empathy, aesthetics (Newen, De Bruin & Gallagher 2018). In addition to 4E, the affective domain is sometimes added (Damasio 1999, Griffith & Scarantino 2005, Colombetti 2014), but Peter Stilwell and Katherine Harman (2019) call it "emotive" in their study of pain and rename 4EA cognition 5E cognition. I will use the latter term.

Embodiment

«12 » Shaun Gallagher (2017) positioned embodied cognition at the juxtaposition of the central nervous system, autonomic and peripheral systems, physical activity, and connection with the environment. The attitude of the individual towards the world depends on how the body is felt, perceived and positioned. Evan Thompson (2005) described a binding link between action (movement) and sensation, creating a sensorimotor loop, but perception is generated by bodily processes and actions in relation to the (social) environment. Edmund Husserl (1989) had already emphasized that human perception is not a passive reception of information, but active, often influenced by our (moving) body. Other authors also observed that our perception of the world, spatial and temporal dimensions, our mode of interacting with objects, and our thoughts are influenced by body movements and body state, such as pain (Lakoff & Johnson 2002).

« 13 » Phenomenological models focus on the experience of illness, as our perceptions of our bodies shape how we experience ourselves, understand the world and our position in it. Phenomenological models also understand illness as something that can develop without a clear underlying physiological dysfunction and may be related to the individual interpretation and evaluation of particular life circumstances or situations (Svenaeus 2009).

"14" The body is a bridge that connects experiences of different sensory modalities, different states (from pain to painless), and different situations. This shapes the body as a lived body. The body does not represent (only) something passive that can be seen, smelled, touched, but our ability to see, smell, touch... In other words, the body is not only an object that can be viewed from the outside, but an authentic source of experience (Honkasalo 2000).

"15 " This accentuates the necessity of considering the physical and subjectively experienced or lived body when inquiring about pain. Embodiment implies interaction with others (including clinicians), so the genuine subject of pain is neither disembodied consciousness nor the physiological body, but the lived body, embodied subjectivity (Geniusas 2020: 11). And pain, dependent on meaning and created through relational interactions, is embodied towards the world, has an attitude towards the world (Honkasalo 2000: 199).

Embeddedness

« 16 » Embeddedness represents the understanding that one is automatically situated in an environment, that cognition is enabled by constant interaction between body and environment, and that perception is situated in interpretations of the context of the current situation (Heidegger 1962; Benner 1994). Further, Gallagher (2018a) argues that our actions involve neural, bodily, social and cultural aspects, all of which are interrelated and dynamically changing. Applied to the field of pain, various authors (Rey 1995; Honkasalo 2000) state that pain is a mixture of bodily processes and subjective experiences shaped by social experiences, cultural and historical norms, religious, moral and philosophical beliefs and specific cognitive reasoning. Pain is thus embedded in many common events and activities.

"17" When considering the dynamics of interactions with the social environment, the predictive model of the world

(Clark 2013) is of great importance. We are constantly trying to predict our environment, predicting expected sensory stimuli or social actions, communicating with others and comparing these assumptions to incoming stimuli, and forming further predictions based on this. Predictive processing influences both our perceptions and our behaviors, as a result of which we also make assumptions and adapt (Clark 2013). Thus, knowledge about ourselves and the environment is actively constructed by an observer, including the function of adaptation (Demšar & Kordeš 2018). The influence of predictive processing has also been demonstrated in clinical practice; during desensitization exposure, errors in expectations and generalizations were relearned according to the new experience and as a result, body sensations changed (Stilwell & Harman 2019).

"18 "> From an embedded perspective, pain is an adaptation to minimize the risk of provoking further pain or (re)injury (van Dieën, Flor & Hodges 2017). The experience of pain is a relational phenomenon that reflects our inseparable interaction with the social and pure sensory environment, such that "to experience one is to experience the other" (Ratcliffe 2008: 1). Although pain can be felt as an experience of the body, it is, more generally, an experience of the interaction between body and environment.

Enaction

«19 » Key concepts of enaction are autopoiesis and structural coupling, the latter being particularly intertwined with embodiment. Autopoiesis or self-production is an essential quality of living systems, a unity of interrelated elements, that create the same network that made them (Maturana & Varela 1980). An autopoietic system is selfindividualizing, self-organizing, self-maintaining, self-making (Demšar & Kordeš 2018) and an adaptive (Di Paolo, Buhrmann & Barandiaran 2017) closed system. Environmental disturbances trigger changes in the system of the organism, and stimulate continuous processes of self-produced identity, thus giving opportunity for one's individuality.

« 20 » As mentioned above (§11), for Merleau-Ponty (2012) the body is lived and intentional, born into the world, but besides

being a subject of knowledge and action, it is also in itself an origin of meaning and in relation to the world. The body (system) influences and is influenced by external processes – body and environment are thus coupled. When the body has the capacity of agency, the coupling can be asymmetric, with the body modulating its coupling with the environment, for example, through sensorimotor interactions with the environment. However, the environment can also be a source of asymmetric coupling (Di Paolo, Buhrmann & Barandiaran 2017).

« 21 » From the autopoietic perspective, it is important to understand that the organism tries to avoid threat and maintain identity. The individual attempts to accommodate a perspective of the world from neutral to phenomenal (Umwelt), and make sense of situations (Weber & Varela 2002). From the medical point of view, pain is a warning signal of a threatening situation and tries to stimulate the organism to change something, to eliminate the threat or to move away from it (Raja et al. 2020). However, what can be so threatening to a person (or her body) that pain endures for more than 6 months (as is a basic lower limit for determining chronic pain)? It seems there are other, perhaps at first glance, less obvious properties of the environment that can cause a sense of threat and in which an individual may feel trapped - adding to the sense of threat. With body movement, different dealings with the environment may be conducted. With a new exchange between the sensorimotor system and the environment, a person may acquire new experiences that reshape their pain perception. This can also happen through an emotional-cognitive response or by changing the attitude towards the environment (Muelders 2019).

"22 " Our coupling with the environment influences our perception of pain and the meaning we will ascribe to pain. We actively control our perceptions as well as our behaviors, interactions, and sense-making. We couple with different subjects and objects and also with more concrete or abstract systems (e.g., past and present), but for the experience of pain, coupling with others is probably most important, since it is through interaction with other people that we create the special aspects of meaning (Park 2013). Hanne De Jaegher and Ezequiel Di Paolo

(2007) introduced the notion of participatory sense-making, which describes how connection with other people creates meaning that cannot be created otherwise. By combining these enactive facets, pain can be described as "a process of unpleasant or distressing sense-making from the perspective of an embedded person attempting to adapt and self-regulate to preserve their embodied identity/existence that is threatened" (Stilwell & Harman 2019: 656).

Extension

« 23 » Andy Clark and David Chalmers (1998) explain that cognition is extended when objects in the environment act as part of cognition, when external resources are considered part of an individual's cognitive processes. They have also determined three preconditions for external components of states, processes, and mechanisms: accessibility, stability-robustness, and reliability (or validity). And when a part of the environment and a part of the mind function equivalently, the former is part of one's cognitive process. Gallagher (2018b) describes how an individual interacts with various strands of the environment through active participation, but extends this interaction of brain-body-environment model, by integrating predictive processing and enactivist (more equal activity between elements) dynamics, to predictive engagement and explaining environmental properties as physical, structural, cultural, and social.

"24" Before all mentioned authors, Merleau-Ponty (1962) comprehended that an individual composes the world and is composed by the world, so one exists in and with the other. In the context of pain, the pain expands from the body, to the whole person binding with the world (Stilwell & Harman 2019). Taking into account the extended component, pain can be understood as "a relational process of sense-making where objects from the environment and other people are part of the process" (Stilwell & Harman 2019: 654).

Emotiveness

"25 " It is known in psychotherapy (e.g., cognitive behavioral therapy) that emotions are interwoven with thoughts, reflected in bodily sensations and influenced by the environment. The James-Lange

theory of emotions states that awareness of bodily changes may also alter emotional experience and other studies support that this is possible (Niedenthal 2007; Price & Harmon-Jones 2015). Thompson and Mog Stapleton (2009) claim that enactivism understands cognition and emotion as containing each other, but also as not being separated from the body, and apply this to sense-making as well. Husserl divides feelings into two groups: feeling-acts (essentially intentional feelings) and feeling-sensations (feelings lacking intentionality). Pain was classified in both groups.

- « 26 » Possible emotional-cognitive enactment, which has already been mentioned, is in the case of pain mostly portrayed with fear, anxiety, and catastrophizing possible consequences of pain (Vlaeyen & Linton 2012; Stilwell & Harman 2019). However, there are some conditions, such as "pain asymbolia," which involve pain sensation but not any sense of unpleasantness or any motivation to avoid or seek relief from pain (Grahek 2007; Kusch & Ratcliffe 2018).
- « 27 » Although phenomenology accounts for the possibility that pain experience can lack the affective dimension or the broader experience of emotion, phenomenological theories usually associate pain experience with an unpleasant affect (Tye 2006; as does Geniusas). Geniusas's and enactivist definitions of pain (respectively) include emotional components, the former as an aversive feeling connected directly with bodily sensation and the latter to wider experience of emotions:
- 66 an aversive bodily feeling with a distinct experiential quality, which can be given only in original first-hand experience, either as a non-intentional feeling-sensation or as an intentional feeling. (Geniusas 2020: 141)
- ef Pain is a relational and emergent process of sense-making through a lived body that is inseparable from the world that we shape and that shapes us. With this perspective the experience of pain cannot be observed or measured, and qualitative pain narrative remains the best available proxy for inferring pain in others. (Stilwell & Harman 2019: 659)

connection with affect (Bain 2013; Grahek 2007; Kusch & Ratcliffe 2018). However, it has been also suggested that the unpleasantness of pain or even suffering does not necessary lead to an inclination to avoid or avoidance of the pain. Therefore, the pain does not need to have a motivational component. Even more, Martin Kusch and Matthew Ratcliffe (2018) emphasize the importance of separating the pain sensation from the affective-motivational component, for which the unlearning of social-culturally conditioned associations (mostly depressive moods, withdrawal, self-pity, anger) of pain is necessary. In the same vein, Jennifer Radden (2009: 115) writes: "pain is less simple, more cognitively mediated, and thus more like an emotion than had previously been

« 29 » As we have seen above, different theories emphasize different aspects or characteristics of the pain experience. Since I have a phenomenological clinical background and consider embodiment important for understanding the mind-body relationship, I was interested in the phenomenological features of the pain experience and whether they are consistent with the constructivist idea. Thus, the aim of the study was to examine how people experience chronic non-cancer pain, and what the basic characteristics of this pain experience are. At the same time, I was interested in how the intensity of the pain affects other aspects of their experience.

Method

« 30 » Since I was interested in in-depth personal experience, a method of case study with phenomenological interviews seemed appropriate. Thus, eleven case studies were conducted, with one researcher carrying out five and the other thirty-two in-depth phenomenological interviews (at least two interviews with each participant), ranging from 55 to 92 minutes. To explore various perspectives of pain experience and to capture participants' understanding of their pain experience, I researched two poles of pain intensity with each participant: at least one situation in which the participant's pain was reduced and one in which it was increased. Participants selected a past ex-

perience, which had to be vivid, clear and as recent as possible. With all participants the less intensive pain experience was investigated first. Micro-phenomenology is a method that can examine experience retrospectively and in depth (Petitmengin 2017). In the interviews, we tried to encourage participants to relive their experiences at the level of the micro-phenomenological criteria (e.g., stabilized attention, absorption in the observed experience, detailed observation and reporting, Petitmengin 2006), but we succeeded at only four interviews. Other reports are mostly lacking in the detailed descriptions that are typical for the micro-phenomenological method. None of the participants was trained in methods of empirical phenomenology or micro-phenomenology or was familiar with detailed introspection. All the interviews were conducted in participants' native language within six months and were audio recorded. The sample size was random; all the participants were patients at the Health Institute for Clinical Psychology established by the Ministry of Health, Slovenia, in the years 2019 and 2020, and had been diagnosed with a chronic pain condition (and met other inclusion and exclusion criteria): six clients had a diagnosis of fibromyalgia (C3, C4, C5, C6, C9, C11, C12), one client had a diagnosis of scoliosis, fibromyalgia and Guillain-Barré syndrome (C1); one client had chronic pain after a work accident left him with extensive whole-body burns, ranging from fourth- to sixth-degree burns (C7); one client had chronic pain after three surgeries for an abdominal hernia (C2); and two clients with complex regional pain syndrome (C8, C10). All participants had had chronic pain lasting from two to seven years, and one had additional experience with a specific neuropathic acute pain (Guillain-Barré syndrome), lasting for five months. In some of the participants the chronic pain had a clear nociceptive cause (extensive burns, hernia), but most of them had chronic pain that is often considered as having no identifiable biological cause or a biological cause that is not related to the chronic pain syndrome. Thus, the inclusion criteria were a diagnosis of chronic pain, the presence of pain typical of their chronic conditions, and willingness to participate in the study, the most important being that they had a desire to explore their experiences. Exclusion criteria were a severe emotional disorder (e.g., major depression and/or anxiety), and the presence of severe acute pain. Nine clients were female and two were male, with the age ranging from 26 to 51 years.

« 31 » Before starting the research, participants received an information sheet and signed a consent form to participate, where they agreed that they were aware of the survey, which was voluntary and anonymized. They also signed a consent form for the audio recording of the interviews, and to indicate understanding that they had the right to conclude any interview and the research at any time. They also granted permission for all the obtained and anonymized data to be used for research purposes. The research was approved by a scientific committee of the University of Primorska and was conducted in accordance with the principles of the Code of Professional Ethics for Psychologists and the provisions of the Declaration of Helsinki. The protection of personal data was ensured by labelling participants with codes, which were separated from the data itself. All details that could reveal the identity of the participants have been changed or deleted. We paid special consideration to the possible adverse effects of reliving experiences of pain, and gave participants the opportunity for additional clinical psychological and psychiatric support.

"32 » After transcribing¹ the interviews, a case-study design was used to examine and evaluate empirical support for the 5E theory of pain by inducing possible new features from the interviews while deducing existing features from the theory. In this way the existing theory can be (re)evaluated. After several steps of vertical coding of each report, horizontal coding was performed to discover recurring themes, consistent with Barney Glasser and Anselm Strauss's constructivist theory of conceptulization of data (Strauss & Corbin 1998). After each coding step, a peer debriefing was conducted to discuss and verify the

codes. In addition, the inter-rater agreement of deductive coding of ten randomly selected transcripts was assessed, showing 95% agreement in coding. Three participants (C1, C6, C7) were asked about their agreement with the created categories, interpretations, and conclusions created, thus additionally ensuring validity, reliability and credibility.

« 33 » The study has certain limitations, mainly methodological. There is much debate about the validity of retrospective research methods, and because I sought to capture participants' understanding of their pain experience at its two extremes (participants' worst pain experience and a situation in which they experienced less pain), I could also examine their current pain experience. Since the participants in the study experience pain all the time, part of the method would be phenomenological but not retrospective and could add not only to the understanding of pain experience but also to the validity of the method. The detailed descriptions and the reduction of satellite dimensions in the reports mostly did not reach the micro-phenomenological level (Petitmengin 2006), even though they were conducted in accordance with the micro-phenomenological method. Many questions were asked to get a more detailed understanding of participants' experience, but they were unable to provide additional details. It is unclear whether the participants were not willing to explore the experience more deeply due to aversion to the pain or due to a lack of introspection ability or training. The latter seem more likely, as their inability to provide detailed descriptions was similar when describing less intensive pain. This suggests it would be appropriate to first train participants in the method of micro-phenomenological observation and reporting. In addition, the sample of participants could be larger and more diverse in terms of diagnosis (e.g., phantom-limb pain), gender, and age. The study could also be improved by using a different, inductive-only coding method, followed by a grounded theory of pain, which would be compared with the 5E theory of

Results and interpretation

« 34 » The results are presented in the same theoretical structure as the theoretical background presented above. Therefore, I first present some cases that emphasize the biomedical and the biopsychosocial view of pain, which also highlight the biological dimension. However, the main focus is to assess and document the empirical support for the enactivists' 5E approach to understanding pain experience in its various qualities. With examples it is apparent that these five components are so often intertwined that it is sometimes difficult to distinguish one E from another. However, the distinction may also be more difficult because the experience of pain is complex and affects all aspects of one's life.

Pain as a biopsychosocial phenomenon

« 35 » Biomedical models and biopsychosocial models emphasize the body. The first one does so intentionally, the second, it seems less intentionally, more through its application, as a consequence of the history and our Western medical culture. The imbalance between all three components (biological, psychological and social) of pain and the importance of the biological component is clear also from patients' reports. They mostly stress the overall importance of bodily sensations in comparison to other parts of experience and experience of these is not clearly present, many doubt in the validity or adequacy of the pain experience. Sometimes this view can by amplified also by other people in their lives (even doctors).

⁶⁶ Before I got the diagnosis it was emotionally very stressful. I had so many diagnostic procedures and none showed there is anything wrong with me. Yet, I felt so much pain, especially in my thighs, a burning pain, in my feet, stinging pain, and in my arms and shoulders a pain that felt like a strong pressure. I asked myself, did I really self-create all those different sensations? Can all these really be just in my head? ⁹⁹ (C6-1-8)

Embodied

« 36 » Experience of pain as it is felt in the body is common in all models and theories that deal with pain, including enactivism and phenomenology. However, these

^{1 |} Interviews and codes were translated for the purpose of this article. Additional and extended parts of the interviews and codebook are included in the supplementary material available at https://constructivist.info/data/17/2/smrdu.docx

two approaches do not consider the body as an object but regard it as object-subject, through first-person experience. This means that the body is a way of experiencing and understanding the world, that we experience the body and the body enables and nurtures other subjective experiences of the world (Svenaeus 2015). Many researchers have already demonstrated that pain changes subjective perception of time (Rey et al. 2017) and space (Valenzuela-Moguillansky 2013), influences future pain experience, and possibly restricts bodily motion and future behavior (Stilwell & Harman 2019).

- 66 I felt such pain I thought I would go mad. I felt like space was squeezing around me. I couldn't breathe. Wherever something touched me it caused more intensive pain. ... Space was narrowing, but time, time has dragged and dragged on like a long snake. It just didn't end. They gave me some strong analgesic in infusion and a sleeping pill and told me it should be better in a couple of minutes. It felt as though these minutes would never end. 57 (C1-19-27)
- "37" Embodiment also reflects how movement influences the pain experience, how the evaluation of bodily functions influences future behavior, which is consistent with Merleau-Ponty's (2012) notion of the body as a subject of knowledge and action, as a lived, intentional being inherent in the world. In addition, the following part of the report also includes the "embedded" facet, which is evident in the participant's relation to the environment.
- 66 At first, I tried to rest as much as possible and since pain increased when I moved I just moved from the bed to the couch. But also with resting, pain was increasing. Before I was dancing, swimming a lot, and then I quit everything. I withdrew from life, because I thought I would feel better, but I didn't get better, just worse. After advice from a psychiatrist I started to go for short walks and started to interact with others again. Pain reduced a bit, but even if it was sometimes worse, I persisted. I understood the dynamic of pain, at least in some part, better. (C11-2-9).
- «38» The experience of pain is undeniable and localizable, but in different situations the localization may change upon observation. Moreover, different bodily

experiences of pain can represent different pain syndromes, which in turn help to distinguish them, giving pain a different meaning and guiding one's behavior. Teaching patients to better perceive the qualitative aspects of their condition, e.g., that pain is not simply described as pain, might make it easier to discern between different conditions (and thus treatment), but it might also be easier for patients to cope when they become aware that pain is not a stable sensation but varies in qualities, some of which are easier to tolerate.

- 66 Is just blunt pain in my thighs in left more than right... Wait. Now is more burning [sensation]. ... Is moving, a kind of spiral movement, many spirals, but is some kind of closed spiral. ... Is like a centimeter wide. Is quite flat, it doesn't go up and down. It is not solid, is a little translucent, it has lines, threads. Threads are solid, but between them is space that is translucent. ... (C1-4-9)
- « 39 » It is hard to place the memory of a painful experience in just one category of enactivism, but based on the examples from reports, this seems to be the most basic category for it, since memory of previous experiences is also present in a body, which can be seen in well-practiced, habitual movements and practices.
- 66 It was such excruciating pain, it is impossible to describe it, I could shoot myself because of it. I was fearful. I didn't fear for the future, I wasn't thinking it would last or anything like that. Fear was connected with a fact that it was such a horrid situation. It was part of just this present situation, it was part of present bodily pain. It came together with pain. ... And I was just lying there, just feeling the pain and fear and suddenly it came to my mind how I learned breathing techniques for reducing the pain of fibromyalgia during my previous rehabilitation process. And I focused on breathing into my stomach, and pain subsided a bit. It wasn't gone, but it was a little more bearable. ⁹⁹ (C1-19-29)
- "40" Previous experiences may change the present perception of the situation and behavior, so that it reduces pain experience. However, when people are in pain, they may fear certain situations might cause additional pain, so they try to protect themselves also in less functional ways. They may avoid

certain situations, reduce movement, or unknowingly tense muscles for long periods of time (Stilwell & Harman 2019). Even in a process of rehabilitation and gradual exposure, they may be reluctant to move due to anticipatory fear of injury or increased pain.

⁶⁶ I tried to exercise, but anything I did led to more pain, so I stopped. Later we discovered I was totally tightened up, probably all the time, but even more when I tried to exercise. I stiffened my whole body, shoulders and arms the most. And I wasn't aware of it. ⁹⁹ (C10-3-2, 3)

Embedded

- « 41 » Matthew Ratcliffe (2008) explains how pathological experiences can modify one's assessment of the nature and diversity of feelings. Also, the experience of interaction between the body and environment may be expressed in bodily sensations, so these are not a necessary consequence of just bodily states. The circular dynamic between body and environment has already been described by Merleau-Ponty, as he described the habitual body as the basis for our attitude or way of living in the world, so that the body settles in every situation and connects us to the world through "operative intentionality" (Merleau-Ponty 2012: 114). Intentionality can only arise in the relationship between the individual and her environment (Lima, Alves & Turato 2014). The object exists and has assigned meaning through the individual's consciousness (Husserl 1989). Merleau-Ponty pointed out that the body moderates the world/environment relationship through intentionality, claiming, "I am conscious of the world through my body" (Merleau-Ponty 2012: 122). However, pain can also alter one's affordances, which James Gibson (1977) defines as action-based possibilities (and consequences) offered by a person's environment.
- 66 When I was unable to do some things, I began to constitute in my mind what was in my surroundings. When I went back to work (after finishing sick leave) and had to walk up the stairs, I first realized how many there are and how steep they are. And by the time I got to the top of the stairs, my thighs hurt with this burning pain, and I hated the stairs, more every day. And I tried to avoid them. Before the pain, I had a pretty positive attitude about the stairs, because all the ar-

ticles say how healthy it is to walk up the stairs as often as possible, and that you don't use an elevator, for example. (C2-6-3)

- "42" A growing body of studies demonstrate that (social) surroundings can increase or decrease pain (coupling), mostly by generating a feeling of safety or threat, respectively (Harvie et al. 2015; Hechler, Endres & Thorwart 2016). As Gallagher (2018a) writes, our constant embeddedness in social contexts is defined by intersubjective and normative rapports, which may elevate or at least provide the possibility for enhancement of one's experience, or not.
- 66 When I was in a hospital everybody was so kind, they were constantly around me and were adjusting my pillows in different ways, so I would experience less pain. The doctor was communicating a lot to me and she described my diseases. Honestly, I didn't remember what she said to me, I didn't really listen, I tried to, but her words, her voice somehow went through me. But it was soothing, from her way of talking to me and caring, I knew I would be better and that all this pain would pass. 97 (C1-18-5)
- « 43 » As noted earlier, safety behaviors can lead to persistent pain and disability, due at least in part to the repetition of maladaptive sensorimotor cycles, changes in nervous system sensitization, conditional learning, and cultural reinforcement that pain requires rest (Stilwell & Harman 2019). On the other hand, active techniques for managing chronic pain generally reduce the pain experience (e.g., Cosio & Lin 2018). This may be related to predictive processing, which attempts to extrapolate the intentions of others, but also to our sensory perception. We are constantly comparing our expected sensory input with incoming stimuli, trying to balance top-down and bottom-up cognitive processes. Our past experiences help us make predictions about possible sensations, behaviors, and/or the evolution of the current situation. Such predictive processing is congruent not only with the embedded feature, but also with embodied and extended cognition (Gallagher 2017; Kahl & Kopp 2018).
- 66 When I was in the hospital, in rehab, they showed us how to move for daily chores, for ex-

ample, in the kitchen, and we were also filmed in the process. At this point, I stopped being afraid that something would hurt me more. (C5-2-4).

"44" Jean-Paul Sartre (1956) described similar experiences and concluded that the quality of pain depends on what one chooses to focus on. Perhaps the pain can subside if one changes activity, e.g., from reading to listening to the radio. However, the quality of the experience is also influenced by the intensity of consumption in the activities or the world in general. Kusch and Ratcliffe (2018: 11) refer to Eugene Minkowski, saying that activity is opposed to waiting, not as passivity, but as expectation. As we live in a goal-oriented society, we are required to behave according to and be engaged by our environment.

Enacted

- « 45 » An important part of the enactive approach is sense-making of the world, an embodied process of actively connecting dots in our life to actively create significance in it. This is even more important since chronic pain becomes a part of identity and sense-making is one process that helps with the positive integration of pain. On the other hand, part of the adaptation of identity to this overwhelming change that chronic pain presents is also maintaining some content of the "previous" identity. This identity challenge is congruent with Husserl's words, "I am not this body, yet I must be it, if this world of mine is to be" (quoted in Geniusas 2020: 139).
- back on the ship [where the explosion happened]. Yes, it hurts, all the time, but I still go running, even if it hurts all night and I have a hard time walking the next day, but I have to get my body used to it if I want to get back. This is me, it [body] will start functioning, it won't be the same, but it will start functioning... again * (C7-20-3)
- "46 " Sense-making has been shown to be a key concept in understanding major changes in the pain experience, particularly significant reductions in pain. Basic sensemaking and participatory sense-making occur through interaction (verbal and nonverbal communication) with others who give meaning or significance to the situation that

one could not achieve alone (De Jaegher & Di Paolo 2007).

- 66 I'm in the hospital, in rehab. We're in the gym, there's six of us, and the occupational therapist is showing us a fairly simple exercise. And I try to do it, but is hard for me, and the neighbor next to me sighs too. We look at each other and start laughing, then we look at each other in the whole group, and we know what is going on, and we all start laughing. It's a relaxed laugh and you can tell we're all coming out of the pain. Each in our own way, because we're all weak there. (C4-2-16)
- "47" Pain is also a special phenomenon because it absorbs our attention and we have a stronger tendency to identify with the pain experience. In terms of identity, the experience of pain may be a consequence of the disturbed balance between self-differentiation (individuation) and self-development. Because pain engages us so holistically, it is also considered a "whole pain experience" and demands responses and confrontations (Geniusas 2020). This results in another ambiguous feature of the pain experience: on the one hand, it has the character of involuntary passivity; on the other hand, it urges us to change.
- « 48 » Participatory sense-making for the evaluation of pain may be even more relevant in the patient-physician relationship because, for the patient receiving medical treatment, any kind of evaluation of the appropriateness of the experience by medical personnel may have a greater impact. The individual regulates the coupling with the environment (e.g., the physician) in order to maintain her self-created identity. The evolving idea of this encounter is that it moves from the mindreading position (third-person position) to the second-person embodied practice and one's own active, cognitive engagement in creating meaning (De Jaegher & Di Paolo 2007). For example, the transition from the doctor "knows" how the patient feels to the dialogue with the patient that enables her to have her own reflections and awareness of her condition.
- ⁶⁶ I don't tell my family or my friends how I feel, that I feel pain or that I'm worried. I tried once and I can still see their worried faces and their changed attitude towards me. So I pretend that I'm positive and that everything is fine. But that's

why I like coming here and talking to you, I can relax and just say whatever I mean, I don't need to be careful that I would hurt you. (C8-6-14)

Emotive

- « 49 » This component is articulated in virtually all reports that express its importance and support the reasoning of Stilwell and Harman, who added it, but other authors (e.g., Brentano 1995; Kusch & Ratcliffe 2018) also emphasize it but do not directly relate it to enactivism. In the context of pain, fear is the most prominent emotion, and can be part of the experience. It usually refers to the fear of further increasing pain or tissue damage.
- When I don't sleep two or three days, I'm more tired, feel more pain, and the constant worry gnaws at me, what if it's worse, what if I have to have another surgery? (C10-13-4)
- « 50 » However, emotions can also facilitate or even cause the pain experience. The feeling of being threatened may have a self-regulatory character, and be perceived as the lived body's resistance to the lived life or its own will, thus helping to stop the flow of the lived life. A relational attitude is suggested here. Saulius Geniusas (2020) also links this to Martin Heidegger's tying of pain to "(un)readiness-to-hand" life (Zuhandenheit). In this, it seems that the more uncontrollable the situation associated with the experience of pain, the more distressing the experience. He also described the concept of Sorge, which is characterized by anticipatory anxiety and the desire to "attend to" or "care for" the world, based on awareness of temporality, mortality and uncertainty of one's existence (Geniusas 2020: 130). Thus, we see that emotions can be an element of experience and process.
- ⁶⁶ I was in pain before, but after the death of my child, it is unbearable. Every movement is extremely painful. ... Yes, I don't want to live anymore, I don't want to be part of this world anymore. Living now seems something very wrong. ⁹⁷ (C2-7-10)

Extended

« 51 » Gallagher (2017) asserts that bodily processes are extensible from the brain to the body to the environment. This is common at the beginning of the coping process of the chronic pain experience as perception of the world changes – movement is different, perception of space and interaction between one's body and space changes, and knowledge of the environment becomes much more important as its elements help the individual with various things, such as maintaining body balance.

66 I constantly observe the world around me, it is totally automatic. I know where anything I can hold on to is, where there is a wall, a fence, a chair, table, lower closet, a traffic sign, a parked car. I also recognize what is more and what is less stable so I adjust a grip to it, automatically. It is not stressful, not anymore, it is just that my personal space is wider. (C3-8-4)

« 52 » Stilwell and Harman (2019) have already considered that objects and people from one's environment are part of the pain process, but this also applies at a more abstract level, and the relationship may be extended to institutions or places in general. Therefore, places where patients feel safe may also be part of extended cognition connected with pain.

66 When I'm in hospital I always feel better, I have less pain, I'm relaxed, there is nothing I have to do, I'm understood. When I come home everything is waiting for me to do it. My family treats me like there is nothing wrong with me, they don't change anything. Sometimes when I step into the house I feel like energy is draining from me. So, I'm glad when I can go back to hospital. (C3-3-22)

« 53 » Based on the patients' reports, it is clear that the biomedical or biopsychosocial model cannot fully capture the experience of chronic pain because the emphasis or distinction of these components is not present in their experiences. However, the enactivist 5E components are present in the reports and thus the appropriateness of the approach can be confirmed. Nevertheless, a major shortcoming is that the components, as theoretically divided, are not divided in clinical practice and are clearly interwoven. In this case, as expected, the embodied, enacted and emotive components are more pronounced, supporting the addition of the last component by Stilwell and Harman (2019). This also points to the personal significance of the pain experience in one's life and its ability to fully absorb one. The phenomenological approach and understanding of pain perception (Geniusas 2020) can also be confirmed, as this experience is indeed manifested as an aversive, non-intentional feeling-sensation or an intentional feeling with experiential quality. Moreover, I would like to stress the importance of understanding the pain experience as a process, and I would add the importance of horizons, both for the development of attitudes toward pain and for making sense of the pain experience.

Horizon of attending to experience

« 54 » Another concept that proved important in understanding the experience of pain is the novel concept of the horizon of attending to experience (HAE). This concept describes how, in order to understand the experience at hand, we need to understand the perspective of awareness, and in this process the most important thing is the initial attitude of turning toward the experience (Kordeš & Demšar 2018, 2021). It is influenced by many factors, from the goal of why one observes a particular experience and the initial attitude towards the experience, to the beliefs and expectations pertaining to the experience. It has already been discussed that the way we cope with pain is determined by our understanding of the context of the pain experience (Geniusas 2020), but I suggest that the HAE even conditions the understanding of the context. In the experience of pain, the usual context is avoidance of suffering, but this is not necessarily so. It can be related to identity development, pure curiosity, wanting to better connect with and understand one's own body, to coupling with the environment so that others can better understand me, etc. So it is an attitude that underlies all 5E.

With Guillain-Barré syndrome, I was already used to the pain and didn't deal with it the same way (as I did with fibromyalgia). It wasn't shock or trauma like with fibromyalgia, it just was. I thought, 'I'm in the hospital now, and this will go away.' I felt safe in the hospital, I felt, 'I was here to get better.' From the beginning, it was different because I already had experience with fibromyalgia, so my attitude changed everything.⁹⁹ (C1-14-3)



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Conclusion

« 55 » In summary, pain cannot be adequately understood with the biomedical model (e.g., medical technology, neuroscience, genetics), but neither can it be reduced to the sum of physical, psychological and social factors (biopsychosocial model). If we still think of pain as something purely or primarily biological, we get stuck because we assume that there is only one concept of the body, the naturalistic one. However, there is another concept, that of the lived body and the self-conscious body. And in order to understand this concept and to understand pain as part of the lived body, we need to understand various aspects of the pain experience, and for this it is necessary to give voice to the patient's experience, i.e., to take a phenomenological view.

"56" Pain (like the body) is to some extent contradictory. To deal with it, one must distinguish between the "sensation of pain" as a psychological experience and pain as a physical phenomenon, e.g., the result of tissue damage (nociception). However, since pain is undoubtedly an embodied experience, the content of the experience of pain can be neither purely psychological nor purely bodily, but is rather an embodied impression that affects embodied consciousness (Geniusas 2020), thus producing an experience. In this way, phenomenology and embodiment combine.

"57" Knowledge of one's HAE seems crucial to understanding the experience of pain. Sartre (1956) already recognized this process by claiming that the quality of pain depends on our focus (attentional horizon) and, in agreement with Husserl (1989), HAE reflects the possibilities of experience. Thus, evaluating the attitude towards pain expe-

rience affects how the experience is given to one and how the 5E components are expressed. In the context of pain, HAE enables us to move between pain as object and subject, with one possible action being self-distancing from the pain experience, so that it does not become part of one's identity. As HAE can be experienced phenomenologically (Kordeš & Demšar 2021), it is not an attitude of avoidance, but an active management of pain.

« 58 » The present theory integrates processes, dynamics and complexity of pain experience representative of enactivism and phenomenological approaches. Embodied, embedded, enactive, emotive, and extended features (structure) are equally important within the experience, and their dynamics are regulated by the perspective of observation (HAE), perception of pain, and understanding of pain. These are the processes that are constantly unfolding during the pain experience; they can be referred to as the organization of the system. In addition, there are other elements that constitute the structure of the pain experience: physical, emotional, cognitive, and social. These elements are shuffled by the process of organization. Thus, emotions can be part of the structure or the organisation, depending on their quality. Looking through the kaleidoscope of pain, HAE would be the front lens that determines the view of all the other elements in that kaleidoscope. Organizational processes (5E) are mirrors and compartments arranged at different angles, and in different sizes and quantities. And the small, colorful elements are emotions, various biological elements, thoughts, etc.

« 59 » Introducing an enactivist and phenomenological view of pain in medicine and in society would also change the way patients understand and cope with pain, e.g., reduce the stigmatization of pain, especially pain that has no clear physiological basis (such as fibromyalgia). In addition, patients become more active, independent, and self-reliant, since they are the ones who can observe the dynamics of 5E. Thus, pain can take on different patterns in their kaleidoscope, even with the same elements.

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