



THE (IN)VISIBLE SITE OF PAIN: A REVIEW OF QUALITATIVE RESEARCH

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ABSTRACT

The current bio-psycho-social model of pain requires profound search of the experience of pain from different spheres of life.

Purpose: The purpose of this publication is to summarize the knowledge of the most common and dominant experiences of chronic pain, discussed in qualitative studies over the last 10 years.

Material and methods: Analysis of publications in the period 2010-2019 indexed in world databases with the main focus on the qualitative studies that aim to describe the essential experiences regarding the nature of chronic pain, pertaining to different spheres of life.

Results: The majority of studies have presented experiences related to the negative effects of chronic pain affecting the individual and all aspects of life—experiences related to: 1) the dominant role of pain; 2) the invisibility of pain; 3) the change or loss of identity and the sense of self; 4) loss of social identity; 5) seeking help.

Discussion: Qualitative research has provided particular insight into the multidimensional experience of pain. The selected qualitative studies reveal topics that determine the essence and significance of pain as a phenomenon. Some poorly explored areas are the impact of depression, anxiety, sleep disturbance, the perception of pain situation, the intensity of pain, memories of past experiences.

Conclusion: A detailed and deep investigation of the subjective experiences of the pain sufferer, prospectively monitored, would be useful to enrich management strategies and improve the quality of life of patients with chronic pain.

Keywords: chronic pain, experience, phenomenological, analysis, qualitative

INTRODUCTION:

Each experience is a specific manifestation of the individual life. Human experience becomes only the personally meaningful, encompassing the experience of oneself interacting with the surrounding world. The experiences are not always clearly defined, meaningful, and conscious [1].

The experience of pain is always a contextual, psychologically and emotionally dependent phenomenon, always real (genuine) for the person (subject) who is experi-

encing it. Its nature is determined by the significance of pain to the subject. Therefore the only truth is the claims of the person experiencing the pain [2, 3]. The experience of pain is defined as: “emotional and psychological factors affecting the way a person interprets or perceives transmitted signals of noxious stimulation, and, conversely, perceptions of the harmful stimuli determine the person’s emotional and psychological reactions to the physical sensations” [4]. Ergo, the body appears to function as a conductor of the experience, playing a crucial role in the process of perception in a certain time and space [2]. If the body is visible to the others (objective body), then the experience of pain is invisible and subjective. Bullington defines the place, where the pain is experienced as a “lived body”. Part of the “lived body” is the objective body, that is the object of the medical science and various therapeutic interventions. While experiencing pain, the “lived body” does not remain silent and the patient draws the physician’s attention towards themselves [5].

Every experience consists of a subject and an object, i.e. the one who experiences and what is being experienced. The object and the subject of the experience enter into certain relationships in a particular situation. Usually, the object of experience is located outside the body. The pain, however, is localized in the body and converts into a source of experience. As it paradoxically turns out, the person is simultaneously the one experiencing and the experience [2].

The meaning of the experience is a product of the consciousness interacting with the object and depends on the value that the subject attributes to the object. According to A. Giorgi, the significance of the experience answers the question “What does experience mean to me?” or what each individual’s concept of the experience is [6]. The meaning of the experience is situational, affects the identity and integrity of the person and is influenced by their past experiences and by other persons’ experiences and beliefs [1]. Thus, the essence of the pain is determined by the individual’s responses to it, based on the meaning the individual assigns to it in a specific situation.

Every experience is personal and subjectivity is where it all originates from. This is the reason phenomenological analyses begin with personal experience through to the general description. Phenomenology is not only philosophy but a qualitative method of research as well, emphasizing the individuality of the experience. Regard-

less of the variety of phenomenological schools and respectively methods, they all focus on the substantial description, analysis and assessment of the meaningful and accessible experiences [7].

Pain as an experience, is a complex and multidimensional phenomenon. Pain experiences vary between individuals and within the individual because of their contextual, emotional, cognitive and meaningful aspects [2].

The purpose of this publication is to summarize the most common, recurring (dominant) experiences in patients with chronic pain related to its essence, researched in qualitative studies over the last 10 years. This analysis would contribute to a deeper and more comprehensive understanding of the nature of pain as an experience and its impact on the overall existence of the sufferers.

MATERIAL AND METHODS:

Analysis of publications in the period 2010 - 2019 indexed in world databases by keywords leading in this issue. The main focus of the analysis is to select qualitative studies that aim to describe the essential experiences regarding the nature of chronic pain, pertaining to different spheres of life and more specifically, "what does it mean to live in pain?" No publications related to:

1. Meta-analyzes
2. Surveys on the experience of chronic pain patients participating in pain management rehabilitation programs
3. Study on the experiences of patients with acute pain and chronic malignant pain
4. Surveys on the experiences of physicians who are involved in the treatment of patients with chronic pain.

Sixteen publications were selected, containing studies aimed at describing experiences of chronic non-malignant pain of different origins in the studied patient groups based on semi-structured interviews, regardless of the phenomenological method used. The individual studies have a different focus on the explored topics. The purpose of the analysis is to identify the most common and recurring experiences related to the meaning of chronic pain in the lives of the suffering ones.

RESULTS:

Thirteen of the sixteen selected studies were conducted in the period 2011-2015. The most commonly implemented method for evaluating and analyzing pain experiences used in six studies is Interpretative Phenomenological Analysis, followed by Giorgi's Four-Phase Phenomenological Method – in four of them. In two studies researchers preferred going with van Manen's phenomenological method. A phenomenological hermeneutic interpretation, a Thematic Analysis by Braun and Clarke and Thematic Content Analysis have been used respectively in separate phenomenological studies. In only one study the authors used, not only Interpretative Phenomenological Analysis, as well as other scales and questionnaires to assess the status of the researched group of patients: Brief Illness Perception Questionnaire and General Self Efficacy Scale [8]. One publication presents the re-

sults of a three-phase longitudinal study examining prospectively chronic pain experiences [9].

Among the researched groups predominant is the group of patients suffering from chronic low back pain with different etiologies [8, 9, 10, 11, 12, 13]. This correlates with its prevalence rate, which is as high as 70% [14]. Specific groups of researched patients are: patients with dysfunctional (somatization) pain incl. fibromyalgia [15, 16], chronic pain among age-differentiated groups: adolescents between 14 and 16 years [17] and adults between 66 and 81 [13].

Despite the diversified phenomenological approaches, the majority of studies have presented experiences related to the negative effects of chronic pain affecting the individual and all aspects of life. One publication exhibits the pain experiences of workers living with chronic pain in rural areas, who have accepted it and continued to perform heavy physical labor in spite of the pain. The authors have analyzed the role of self-efficacy for the positive attitude towards the problem related to the possibility of rethinking and re-evaluating their priorities in life, stimulating social sustainability and adaptability [8]. The influences of other factors on the subjective experiences of chronic pain such as depression, anxiety, sleep disturbance, the manner the situation is perceived in during the pain, as well as past experiences of pain are poorly studied areas.

The summary data from selected qualitative studies indicate that participants share experiences across different life and personality spheres. We have identified five main themes of experience:

- 1) Experiences related to the dominant role of pain over the overall existence.

These include: experiences related to the pain's control over the patients' lives; "life is not worth living"; "Pain is the master"; "All life is seen through pain"; experiences related to the unpredictability of pain; [10, 11, 12, 15, 18]; pain as injustice [19]; experiences that define pain as relentless, continuous, and limiting existence with loss of autonomy [13]. Therefore, the pain is unpredictable, continuous and constant. The pain of restraint in all spheres of life.

- 2) Experiences related to the invisibility of pain.

The invisibility of pain contributes to the limitations of its diagnosis and management, as well as to the lack of understanding by the healthcare professionals and the patient's inner circle [11,16]. Invisibility is a prerequisite for a disturbance of mutual trust between doctor and patient, provoking experiences of frustration and a feeling of dissatisfaction with the life of the suffering ones. On the other hand, sufferers experience a misunderstanding of physically healthy people, who have never experienced chronic pain. This causes them to isolate themselves from others as a way of protection [20, 21, 22]. The invisibility in the core of the dualistic nature of pain – on the one hand, pain is physical (material and visible) and on the other is subjective (intangible and invisible) [23]. Juuso et al. have examined fifteen women with fibromyalgia, manifesting with chronic diffuse muscular pain syndrome with unclear etiology and pathophysiology with multiple com-

plaints: diffuse pain, pressure sensitive points, autonomic disorders, headache, arthralgia, disturbed sleep, chronic fatigue and more. The authors have found that fibromyalgia sufferers experience the double burden of their pain. They experience the negative effects beyond the physical (visible) as well as the invisible aspects of pain. The latter raises doubts about their real existence and underestimation of their health problems [14, 15].

3) Experiences related to the change or loss of identity and the sense of self or pain as a threat to identity.

That group of experiences includes: a change in the sense of self, associated with unacceptance of pain and a denial of the problem; difficulties in maintaining self-esteem and dignity; hopelessness, despair and fear of pain; experiences of anxiety and guilt that they present a burden to their relatives; loss of sense of independence; experiences of shame and powerlessness; experiences of uncertainty, fear of the future, doubts about their coping abilities [11, 20, 24].

4) Experiences related to changes in social status and social roles (loss of social identity).

They comprise of experiences of loneliness, misunderstandings and social isolation (“pain like loneliness and silence”); loss of social contacts, feelings of rejection by healthcare professionals, family and friends; experiences of social injustice [12, 17, 19, 21, 22].

5) Experiences related to seeking help: feeling insult and disparaging their problems, feeling abandoned by the healthcare system, disappointments in regards to unrealistic expectations of treatment outcomes [16, 22].

DISCUSSION:

The pain is invisible and the experiences of pain cannot be objectively researched using a device. The only way to disclose the meaning and the essence of pain is through a confidential dialogue with the sufferer. Phenomenology provides a holistic approach to understanding chronic pain.

The chronic pain experience destroys the natural relation between the body and the world. That defines pain experiences as multifarious and multidimensional, forming a mosaic of interconnected and interdependent experiences. It is impossible for a single experience to disclose the essence of chronic pain in depth. Pain plays a dominant role, controlling the thoughts of sufferers. In this instance, all life is seen through pain. Pain as a chronic disease is constant (persistent) with interrupting functions in overall psychosocial functioning. One of the selected studies represents pain experiences prospectively, proving their constant and unchanging nature over time, which is associated with losses in all areas of life. Researchers have found that the reason for the persistence of experiences is a rejection of pain and focusing on its physical aspects [9]. Unlike acute pain, chronic pain is unavoidable, provoking a sense of uncertainty and ambiguity projected into the future. Experiences of the dominant role and persistence of chronic pain have been investigated in patients with degenerative joint diseases and chronic low back pain.

Pain is unpredictable, associated with fear of pain,

heightening of one’s vigilance and symptoms of anxiety. Negative emotions such as fear and anxiety, create a sense of uncertainty and a loss of independence. Unpredictability as an experience is associated with an experience of uncertainty and fear of the future.

Another recurring theme among selected publications is the invisibility of chronic pain. The pain is subtle and invisible to others, which provokes feelings of being misunderstood by them and being alone in the suffering. Pain is deceptive for others and for this reason chronic pain sufferers are considered by their relatives and healthcare providers to simulate or aggravate their symptoms. Lavie-Ajayi and co-authors define pain as a double-faced phenomenon – on the one hand, it is visible and vivid, but on the other, it is elusive and even deceptive. This dualistic nature of pain is exactly what provokes not only clinicians, but the patients themselves to doubt its reality. The internal struggle during the sharing of experiences that simultaneously deny and ignore the pain, while at the same time acknowledging the reality of the condition, the authors refer to as a “narratological distress” [23]. According to Juuso and co-authors, women suffering from fibromyalgia have a doubly-burdened life. They suffer not only from the physical (visible) aspects of the pain but also from the doubt about whether its existence is real for their close ones (invisible aspects). Experiences related to the invisibility and elusiveness of pain are prevalent among patients with dysfunctional pain, including fibromyalgia, where pain cannot be fully validated by objective examination methods. The experiences of loneliness, being misunderstood, socially isolated, insulted, having their problems disparaged and being abandoned by the health care system result from the experiences related to the invisibility of chronic pain.

Patients with chronic pain suffer not only from the physical aspects of pain and discomfort but also from the loss of identity. They feel alienated and detached from things that previously gave their life meaning. Chronic pain disturbs and interrupts the processes associated with achieving different goals in life, planning future tasks, influencing one’s social status, a sense of independence (autonomy) and a sense of self.

Therefore, subjective experiences related to chronic pain go beyond its sensory, emotional and cognitive aspects, encompassing interpersonal and social spheres. The selected qualitative studies reveal topics that determine the essence and significance of pain as a phenomenon and contribute to its understanding in depth. Few studies have examined the impact of factors such as depression, anxiety, sleep disturbance on pain experiences. Other poorly explored factors involved in the formation of pain experiences are the way in which the pain situation is perceived, the intensity of pain, and memories of past pain. Investigating the impact of the factors listed above, but prospectively monitored, would be useful to in-depth studying of chronic pain experiences as a phenomenon, as well as finding individual approaches to managing them in order to improve the quality of life of patients with chronic pain.

CONCLUSION:

Pain is a phenomenon with a double nature, possessing both visible (physical) and invisible (subjective) aspects. The invisible side of pain is comprised of subjective and personal experiences. Chronic pain, due to its constancy and persistence over time, provokes experiences related to inevitability and continuity. The invisibility provokes doubts about its actual existence, which gives rise to the feeling of being different, unintelligible and rejected. Chronic pain has intermittent functions about health, sense of self, lifestyle, social roles, future goals and objectives. It affects the physical, mental and social well-being.

Chronic pain is an invisible state that cannot be measured objectively. The invisibility of pain contributes to limitations in the processes of diagnosis and management of pain, as well as to a lack of understanding by medical professionals. The introduction of phenomenological methods when examining patients with chronic pain in day-to-day practice as a routine tool would facilitate the processes of individualized assessment and selection of therapeutic approaches. Such a method of exploring the essence of pain experiences would reduce the experienced double burden and would help build a relationship of confidence between doctor and patient.

REFERENCES:

1. Aleksandrov I. [Personal regulatory processes in hospital environment. Principal directions in psychological aid.] STENO, Varna. 2015; p. 38-39. [in Bulgarian]
2. Merleau-Ponty M. Phenomenology of perception. Padstow: Routledge and Kegan Paul; 2009. pp 235-283.
3. Saariaho T. Chronic pain, depressiveness and pain disability. The role of early maladaptive schemas among Finnish pain patients and control sample. [Dissertation] University of Tampere. 2012. pp 16-30. [Internet]
4. Eimer BN, Freeman A. Pain Management Psychotherapy: A Practical Guide. 1st Edition. Wiley. February 23, 1998. [internet]
5. Bullington J. Embodiment and chronic pain: Implications for rehabilitation practice. *Health Care Anal.* 2009 Jun;17(2):100-9. [PubMed] [Crossref]
6. Giorgi A. The Descriptive Phenomenological Psychological Method. *JPP.* 2012 Jan;43(1):3-12. [Crossref]
7. Davidsen AS. Phenomenological Approaches in Psychology and Health Sciences. *Qual Res Psychol.* 2013 Jul;10(3):318-339. [PubMed] [Crossref]
8. Dean SG, Hudson S, Hay-Smith EJC, Milosavljevic S. Rural Workers' Experience of Low Back Pain: Exploring Why They Continue to Work. *J Occup Rehabil.* 2011 Sep;21(3):395-409. [PubMed] [Crossref]
9. Snelgrove S, Edwards S, Liossi C. A longitudinal study of patients' experiences of chronic low back pain using interpretative phenomenological analysis: Changes and consistencies. *Psychol Health.* 2011 Feb; 28(2):121-38. [PubMed] [Crossref]
10. Ojala T, Häkkinen A, Karppinen J, Sipila K, Suutama T, Piirainen A. The Dominance of Chronic Pain: A Phenomenological Study. *Musculoskeletal care.* 2014 Sep;12(3):141-9. [PubMed] [Crossref]
11. Ojala T, Häkkinen A, Karppinen J, Sipila K, Suutama T, Piirainen A. Chronic pain affects the whole person — a phenomenological study. *Disabil Rehabil.* 2015; 37(4): 363-71. [PubMed] [Crossref]
12. Bailly F, Foltz V, Rozenberg S, Fautrel B, Gossec L. The impact of chronic low back pain is partly related to loss of social role: A qualitative study. *Joint Bone Spine.* 2015 Dec; 82(6):437-41. [PubMed] [Crossref]
13. Stensland M, Sanders S. Living a Life Full of Pain: Older Pain Clinic Patients' Experience of Living With Chronic Low Back Pain. *Qual Health Res.* 2018 Jul;28(9):1434-1448. [PubMed] [Crossref]
14. Milanov I. [Pain.] *Medicina i Fizkultura.* Sofia. 2016; p.198-216. [in Bulgarian]
15. Juuso P, Skär L, Olsson M, Söderberg S. Living with a double burden: Meanings of pain for women with fibromyalgia. *Int J Qual Stud Health Well-being.* 2011; 6(3) [PubMed] [Crossref]
16. Ojala T, Häkkinen A, Karppinen J, Sipila K, Suutama T, Piirainen A. Although unseen, chronic pain is real – A phenomenological study. *Scand J Pain.* 2015 Jan;6(1):33-40. [PubMed] [Crossref]
17. Forgeron PA, Evans J, McGrath PJ, Stevens B, Finley GA. Living with difference: exploring the social self of adolescents with chronic pain. *Pain Res Manag.* 2013 Nov-Dec;18(6):e115-23. [PubMed] [Crossref]
18. Ojala T, Häkkinen A, Karppinen J, Sipila K, Suutama T, Piirainen A. Revising the negative meaning of chronic pain – A phenomenological study. *Chronic Illness.* 2015 Jun; 11(2):156-67. [PubMed] [Crossref]
19. McParland JL, Eccleston C, Osborn M, Hezsetline L. It's not fair: An Interpretative Phenomenological Analysis of discourses of justice and fairness in chronic pain. *Health (London).* 2011 Sep;15(5):459-74. [PubMed] [Crossref]
20. Hearn JH, Cotter I, Fine Ph, Finlay KA. Living with chronic neuropathic pain after spinal cord injury: an interpretative phenomenological analysis of community experience. *Disabil Rehabil.* 2015 Jan;37(23): 2203-11. [PubMed] [Crossref]
21. Dow CM, Roche PA, Ziebland S. Talk of frustration in the narratives of people with chronic pain. *Chronic Illn.* 2012 Sep;8(3):176-91. [PubMed] [Crossref]
22. Tollefson J, Usher K, Foster K. Relationships in pain: The experience of relationships to people living with chronic pain in rural areas. *Int J Nurs Pract.* 2011 Sep;17(5):478-485. [Crossref]
23. Lavie-Ajayi M, Almog N, Krumer-Nevo M. Chronic pain as a narratological distress: a phenomeno-

logical study. *Chronic Illn.* 2012 Sep; 8(3):192-200. [[PubMed](#)] [[Crossref](#)]
24. Smith BE, Moffatt F, Hendrick P, Bateman M, Rathleff MS, Selfe J, Smith TO, Logan P. The experience of living with patellofemoral pain—loss, confusion and fear-avoidance: a UK qualitative study. *BMJ Open.* 2018 Jan 23;8(1):e018624. [[PubMed](#)] [[Crossref](#)]

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