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Mini Review

"Please, don't take my illness away from me!!" Considerations about Some Clinical Vignettes from the Daily Life of a Pain Therapy Center

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Background

According to international guidelines, the mission of a Pain Therapy Center is to perform a complete patient evaluation aimed at reaching an accurate pain diagnosis, that is the cornerstone for a correct and appropriate treatment [1]. However, in real life, some Chronic Pain (CP) diagnoses seem to be sometimes performed without considering evidence-based criteria and are therefore questionable or even inconsistent [2]. Among these, common are diagnoses of various types of "neuralgias" or other pain entities such as "algodystrophies" (actually named Complex Regional Pain Syndromes), undefined "arthropathies", or even extremely rare diseases, which resulted completely unsupported by accepted diagnostic criteria at a critical re-evaluation. Interestingly, some patients make these diagnoses their own, and it is difficult or impossible to question them. In fact, the severe prognosis of the disease, even if inconsistent with the clinical and instrumental data, seems to be an insufficient reason for the patient to question it, especially if this diagnosis was formulated many years ago. Moreover, inappropriate pain treatments are proposed or continued without any benefit and often only with relevant side effects [3]. This would therefore constitute a sort of "appropriation" of the illness by the patient who does not accept any questioning and opposes all critical review of his clinical picture. The aim of this paper is to convey some considerations about this problem, taking inspiration from three clinical exemplificative vignettes from the real life of a Pain Center, and making some suggestions for daily clinical practice.

Vignette 1: The Ankylosing Spondylitis

A 46-year-old female patient refers to our pain center complaining of chronic widespread pain, mainly localized in the back, sleep disturbances, unrefreshed awakening, and cognitive problems. Other symptoms were also evidenced (Irritable Bowel Syndrome, headache, pelvic pain and others). While this clinical picture was deeply suggestive for Fibromyalgia Syndrome (FMS), this symptomatology, dating from several years, was initially attributed, by one of the first clinician who evaluated the patient, to a form of "ankylosing spondylitis" despite having completely no radiographic, laboratory or instrumental evidence, both at the time of the initial evaluation and also over the years [4]. Furthermore, several pharmacological treatments were attempted, starting from steroids, NSAIDs, and many others, including the latest generation of biological drugs, without any therapeutic efficacy. Nevertheless, when we questioned this diagnosis, the patient reacted vehemently, rejecting any new diagnostic hypothesis and questioning the competence of the new clinicians. Given the situation, the visit concluded quickly, and the patient did not show up for the subsequent follow-up visit.

Vignette 2: The Glossopharyngeal Neuralgia

A 73-year-old female patient refers to the pain center complaining of chronic deep and continuous pain in the left anterior side of the neck. This pain dates back almost 40 years, and several practitioners proposed different scenarios, several possible diagnoses, and various therapeutic approaches (pharmacological and non-pharmacological, including some invasive treatments), which have proven to be completely ineffective over time. The documentation showed an incredible amount of in-depth instrumental and laboratory examinations, which, however, failed to highlight any pathological evidence. Among the hypothetical diagnoses that had been proposed during the years, the patient seemed to have identified her pathology as a form of "glossopharyngeal neuralgia", despite the referred symptoms being inconsistent with this well-known but very rare painful illness [5]. Even after reading herself the diagnostic criteria for glossopharyngeal neuralgia during the evaluation and agreeing that they did not correspond absolutely to the symptoms complained of, the patient continued to claim that this was her pathology and did not accept any alternative diagnostic option. Then, the patient left the visit suddenly very upset and without saying any other words.

Vignette 3: The Knee Algodystrophy

A 42-year-old male patient refers to our pain center complaining of left knee pain, for about 1 year, after a negligible indirect trauma during walking on the street. The patient reported a localized, continuous and excruciating pain in the medial upper side of the left knee, in a very small area, completely refractory to all painkillers, described as burning, gnawing, pulsating, or like a "scraper". All the instrumental and laboratory evaluations were completely inconclusive, and a diagnosis of "idiopathic knee pain" was performed. Nevertheless, a diagnosis of "algodystrophy" was previously proposed by a clinician during its evaluation, and the patient consequently undergoes ineffective bisphosphonate treatment, despite this hypothesis being inconsistent in respect to the clinical picture and all accepted diagnostic criteria [6]. Several treatments other than pharmacological, like invasive procedures (direct infiltration of steroids and local anesthetics, intra articular injections), electrical percutaneous stimulations, and also acupuncture were totally ineffective. After ten months, pain spread with the involvement of the entire left lower limb, pelvis, perianal area, dorsal and lumbar area, always unilateral, with severe depression, reduced daily activities, and disturbed sleep. Also, in this situation, no sign of any detectable disease was evidenced after yet another in-depth instrumental and laboratory re-evaluation. Despite this scenario, the patient refuses the diagnosis of idiopathic pain and, based on their deep-rooted belief of really having an algodystrophy, after an online search, requested from us a Spinal Cord Stimulation (SCS) implant, which was rejected due to the inconsistency of the diagnosis. Nevertheless, an SCS implant was also attempted at another medical center, but it was completely unsuccessful.

Discussion

Why do patients not seem to want to abandon their diagnosis, even when this change could lead to different treatment opportunities? A broader reasoning needs to be made, considering all the variables at play in living with a chronic illness like CP. Illness breaks into our present narrative like a fracture, necessitating a revisitation of the past and of the future. The health-related quality of life significantly decreases when disabling and pain-related symptoms persist over time, and patients frequently report feeling disbelieved, experiencing delays in diagnosis, and repeated dismissals by clinicians [7-12]. Several studies determined that CP represents a foundational disruption to one's identity, often degrading a person's temperament, leading to the failure to fulfill their roles within close relationships and "corroded sense of who they were as individuals and their self-worth" (p. 132, (13)) [11-16]. For these reasons, living with CP can often change how individuals think about their overall sense of self [14-17]. Patients with CP find themselves having to survive a precarious balance. On the one hand, they try to reduce the interference of the disease in their daily life, even at the cost of normalizing what does not seem possible. On the other hand, they need to understand and reject uncertainty, promoting the search for decisive or ameliorative interventions, but still validating their suffering. This, therefore, translates into a conflict between answer-seeking, rejection and survival. To cope with the difficulties related to illness, patients usually identify the areas where it is possible to maintain a sense of agency and self-efficacy and adapt the modulation of their identity around their disease [18]. Embracing a sense of self, in which different self-assets are integrated into a coherent whole with illness identity, can improve life satisfaction and psychological well-being, contributing to reducing the sense of illness intrusiveness [19-22]. Illness identity can be defined differently, according to the degree to which the illness is integrated into personal identity. Charmaz described four different constructions. In the Acceptance context, the illness is a part of the patient's identity without being overwhelmed; in Enrichment, some patients feel that the illness enabled them to grow as a person, leading to a change in their values and how they look at life. In the Engulfment, patients define themselves entirely in terms of their illness. In the Rejection, the illness is rejected as part of the patient's identity and is seen as a threat or as unacceptable [23].

Acceptance and enrichment might enable patients to deal better with the challenges of the illness, and acceptance leads to better self-care behaviors [24,25]. Rejection identity is significantly correlated with a more significant perceived impact of illness characteristics, more uncertainty, and more threatening illness perceptions [26,27]. Worse physical functioning, in terms of pain and illness symptoms, and increased anxiety-depressive symptoms are related to engulfment, even if the relationship between illness identity and illness severity is not always clear [25,28,29]. Therefore, there seems to be evidence of a negative association between non-integrative dimensions of illness identity, like engulfment or rejection, with adherence and worse health-related outcomes. It is possible that, as in the three cases we described, the patient reacts with a defensive closure to any possible alternative to already defined diagnostic labels. This is because any change in diagnosis is perceived as threatening the sense of identity that the patient has built thanks to the illness. Closure to any change is stronger the more there is overlap and cohesion of self to illness identity. A communication that conveys a fracture or an invalidation of an illness-based identity structure is felt as an attack on the self as a whole, as it coincides with losing past, present, and future narratives [12]. Therefore, losing an illness-based identity is perceived as more threatening than the symptomatology itself. Long stories of suffering involve the constant search for answers, in which the communication of the diagnosis is a decisive moment in seeing parts of oneself that are difficult to accept and to live with, finally recognized. This would partly explain the affection that patients show towards the diagnosis they manage to obtain and the difficulty in abandoning them for paths that are once again uncertain, and which represent a moment of rupture of such complex integrity of the self-image.

Implications for Clinical Practice

The "illness appropriation" is a critical issue in CP and must be approached by Algologists from different points of view. From a general perspective, the cornerstone of the Pain Therapy Practice is the diagnostic appropriateness, considering the above-mentioned implications of pain diagnosis on the patient's physical and mental health [3]. As correctly stated, it is not clinically meaningful to diagnose signs and symptoms unless they are associated unequivocally with a recognizable pain syndrome that can be discriminated against by others, having different implications with regard to prognosis and treatment. Only in this way is it possible to minimize the degree to which unrecognized patterns are confused with unpredictable patterns, thus reducing diagnosis to guesswork [30]. In the limit, diagnosis is determined by the degree to which processes having different clinical manifestations can be recognized as relevant alternatives [30]. Thus, a careful and complete patient evaluation, including medical history, allows a correct diagnosis and a personalized treatment plan. In addition, an appropriate diagnosis stratification among CP patients allows to moderate the large variability in the individual response to even the most efficacious pain treatments observed clinically, which has led to calls for a more personalized, tailored approach to treating patients with pain, in the so-called "precision pain medicine" [31]. Unfortunately, this goal in some CP scenarios, where signs and symptoms are not completely understandable and often overlap between different syndromes and diseases, may be particularly challenging and at risk of diagnostic mistakes. In fact, laboratory and/or instrumental in-depth investigations, even if correctly requested and performed, are often not able to lead to a definite diagnosis, but are important at least in the diagnosis of exclusion of specific and well-defined pain diseases. In these contexts, in our opinion, the pain therapist must be particularly cautious, avoiding incongruent diagnosis only to please the patient or justify some particular treatments which are more familiar or confident to him. Moreover, one must be aware that some diagnostic labels crystallize in the patient's memory and become tools for misinterpreting reality. On the other hand, the pain clinician must also take into consideration the concept of disease identity and how CP impacts on a patient's daily life. To approach this aspect, it must be carefully evaluated whether the patient is ready to reconsider another possible diagnosis and if there is a need for a more cautious approach to avoid disrupting the therapeutic alliance and provoking strong resistance to any intervention that might challenge a sense of self so laboriously achieved. In general terms, we believe that the option of a diagnostic revision must be taken into consideration, particularly in patients undergoing inappropriate, ineffective, and threatening treatments, which can negatively impact the global patient's Quality of Life. This is particularly relevant in some pharmacological treatments in CP, like opioid medications, which have been shown to be severely dangerous for particular patient populations, as demonstrated by the devastating opioid epidemic still affecting many countries around the world [32]. In these situations, it is necessary to investigate whether the patient is willing to reconsider their clinical conditions in a non-traumatic way, eventually postponing this process over time when the relationship with the patient has strengthened. In fact, it has been demonstrated that maximizing Therapeutic Alliance (TA)-promoting behaviors from the very start of patient interaction positively correlates with pain intensity at baseline and during the therapeutic process [33]. This aspect must be particularly important if the patient requests specific and expensive treatments like neuromodulation procedures. In this case, a different diagnostic and therapeutic option may be carefully proposed to avoid inappropriate treatments. On the contrary, if changing a diagnosis has no clinical need and would not change the patient's condition, this revision can be avoided, bringing no benefit to either the clinician or the patient. Finally, some patients require a medical second opinion by a Pain Clinician not only for therapeutic reasons but mostly for insurance, compensation, or reimbursement litigation, often related to post-traumatic outcomes after work or motor vehicle accidents or iatrogenic injuries. In this scenario, the Pain Clinician must try to understand the real reasons behind the second opinion and critically evaluate the patient's clinical picture and documentation. An alternative diagnosis can be proposed at least as a working hypothesis, avoiding simply recopying previous diagnoses that appear unfounded in his judgment. Furthermore, correlations with clinical and instrumental data must be carefully evaluated, precisely correlating any pain generator to the characteristics of the pain complained of by the patient.

Conclusions

Illness appropriation is a relevant concern in pain medicine and must be approached carefully by clinicians. An accurate and substantiated pain diagnosis, if possible, is mandatory not only for a subsequent therapeutic approach but also to avoid crystallizing erroneous beliefs in the patient. A diagnostic review can be considered on an individual basis, weighing benefits and risks with particular regard to behavioral aspects, the impact of treatments, and the consequences on the therapeutic alliance.

References

1. Rahman S, Kidwai A, Rakhamimova E, Elias M, Caldwell W, et al. (2023) Clinical diagnosis and treatment of chronic pain. Diagnostics (Basel) 13: 3689.
2. Hendler N (2016) Why chronic pain patients are misdiagnosed 40 to 80% of the time? Journal of Recent Advances in Pain 94-98.
3. Carnago L, O'Regan A, Hughes JM (2021) Diagnosing and treating chronic pain: Are we doing this right? J Prim Care Community Health 12: 21501327211008055.
4. Agrawal P, Tote S, Sapkale B (2024) Diagnosis and treatment of ankylosing spondylitis. Cureus 16: e52559.
5. Headache Classification Committee of the International Headache Society (2018) The International Classification of Headache Disorders, 3rd edition. Cephalalgia 38: 1-211.
6. Goebel A, Birklein F, Brunner F, Clark JD, Gierthmühlen J, et al. (2021) The Valencia consensus-based adaptation of the IASP Complex Regional Pain Syndrome diagnostic criteria. Pain 162: 2346-2348.
7. Hadi MA, McHugh GA, Closs SJ (2019) Impact of chronic pain on patients' quality of life: A comparative mixed-methods study. J Patient Exp 6: 133-141.
8. Svenaeus F (2011) Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. Med Health Care Philos 14: 333-343.
9. Kragting M, Pool-Goudzwaard AL, Coppieters MW, O'Sullivan PB, Voogt L (2024) Illness perceptions in people with chronic and disabling non-specific neck pain seeking primary healthcare: A qualitative study. BMC Musculoskelet Disord 25: 1-15.
10. Ross WT, Snyder B, Stuckey H, Ross IR, McCall-Hosenfeld J, et al. (2023) Gynaecological care of women with chronic pelvic pain: Patient perspectives and care preferences. BJOG 130: 476-484.
11. Edlund SM, Wurm M, Holländare F, Linton SJ, Fruzzetti AE, et al. (2017). Pain patients' experiences of validation and invalidation from physicians before and after multimodal pain rehabilitation: Associations with pain, negative affectivity, and treatment outcome. Scand J Pain 17: 77-86.
12. Nicola M, Correia H, Ditchburn G, Drummond P (2021) Invalidation of chronic pain: A thematic analysis of pain narratives. Disabil Rehabil 43: 861-869.
13. Stensland M, Sanders S (2018) Living a life full of pain: Older pain clinic patients' experience of living with chronic low back pain. Qual Health Res 28: 1434-1448.
14. Aldrich S, Eccleston C (2000) Making sense of everyday pain. Soc Sci Med 50: 1631-1641.
15. Miles A, Curran HV, Pearce S, Allan L (2005) Managing constraint: The experience of people with chronic pain. Soc Sci Med 61: 431-441.
16. Charmaz K (2018) Struggling for a self: Identity levels of the chronically illness. In J. A. Roth & P. Conrad (Eds.), Research in the Sociology of Health Care: The experience and management of chronic illness (Vol. 6, pp. 283-321). JAI Press.
17. Voorhees HL (2022) "I was literally just not myself": How chronic pain changes multiple frames of identity. Health Commun 38: 1641-1653.
18. Charmaz K, Rosenfeld D (2010) Chronic illness. In W. C. Cockerham (Ed.), The new Blackwell companion to medical sociology (pp. 312-333). Wiley-Blackwell.
19. Bellizzi KM, Blank TO (2007) Cancer-related identity and positive affect in survivors of prostate cancer. J Cancer Surviv 1: 44-48.
20. Campbell JD, Assanand S, Paula AD (2003) The structure of the self-concept and its relation to psychological adjustment. J Pers 71: 115-140.
21. Graham CD, Gouick J, Krahé C, Gillanders D (2016) A systematic review of the use of acceptance and commitment therapy (ACT) in chronic disease and long-term conditions. Clin Psychol Rev 46: 46-58.
22. Morea JM, Friend R, Bennett RM (2008) Conceptualizing and measuring illness self-concept: A comparison with self-esteem and optimism in predicting fibromyalgia adjustment. Res Nurs Health 31: 563-575.
23. Charmaz K (1995) The body, identity, and self: Adapting to impairment. Sociological Quarterly 36: 657-680.
24. Van Bulck L, Luyckx K, Goossens E, Oris L, Moons P (2019) Illness identity: Capturing the influence of illness on the person's sense of self. Eur J Cardiovasc Nurs 18: 4-6.
25. Oris L, Luyckx K, Rassart J, Goubert L, Goossens E, et al. (2018) Illness identity in adults with a chronic illness. J Clin Psychol Med Settings 25: 429-440.
26. Mozzetta A, Antinone V, Alfani S, Neri P, Foglio Bonda PG, et al. (2008). Mental health in patients with systemic sclerosis: A controlled investigation. J Eur Acad Dermatol Venereol 22: 336-340.
27. Heidlebaugh AR (2020) Illness identity and psychological adaptation in individuals with hypermobile Ehlers Danlos syndrome or hypermobility spectrum disorder (Doctoral dissertation, Johns Hopkins University).
28. Shneider CE, Robbertz AS, Cohen LL (2024) A systematic review of relationships between illness identity and health-related outcomes in individuals with chronic illnesses. J Clin Psychol Med Settings 31: 130-142.
29. Rassart J, Van Wanseele C, Debrun L, Matthijs K, Moons P, et al. (2023) Illness identity in inflammatory bowel disease. Int J Behav Med 30: 77-88.
30. Webber RL, Groenhuis AJ, Ruttimann UE (1985) Pain and the diagnostic process: conceptions and misconceptions. Anesth Prog 32: 13-18.
31. Edwards RR, Schreiber KL, Dworkin RH, Turk DC, Baron R, et al. (2023) Optimizing and accelerating the development of precision pain treatments for chronic pain: IMMPACT review and recommendations. J Pain 24: 204-225.

32. Phillips JK, Ford MA, Bonnie RJ (Eds.) (2017) Pain management and the opioid epidemic: Balancing societal and individual benefits and risks of prescription opioid use. National Academies Press.
33. Myers C, Thompson G, Hughey L, Young JL, Rhon DI, et al. (2022) An exploration of clinical variables that enhance therapeutic alliance in patients seeking care for musculoskeletal pain: A mixed-methods approach. Musculoskeletal Care 20: 577-592.