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Review Article

Can We Diagnose Suffering in Patients?[1]

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Abstract

Eric Cassell introduced his demand that physicians be more attentive to assessing the suffering of their patients as one of the fundamental goals of medicine. This call was indeed taken into account by health professionals but remained difficult to satisfy in the absence of appropriate measures. In addition, the focus on end-of-life suffering in palliative care has excluded, in the vast majority of cases, patients with chronic medical conditions like chronic pain whose on-going suffering is part of everyday life. To fill this gap, my integrative approach relies on both philosophical, psychobiological and clinical concepts seeking to provide a measure accompanied by an interpretation of the person's suffering. The practical goal is to provide a simple and effective clinical tool to assess the degree of suffering related to pain and to characterize its specific nature in each patient, allowing a more precise diagnosis and more individualized management of chronic patients. In specifically answering the question « Can we measure Pain- related Suffering? », this article addresses the main issues, both conceptual and methodological, attached to the diagnosis of suffering using pain as a study case in order to instruct the development of an illness-related suffering assessment tool for medical use.

Keywords: *Human Suffering; Chronic Pain; Measurement; Meaning; Suffering Assessment Tool; Chronic Illnesses; Philosophy; Experimental Studies; Clinical Studies*

Introduction

Over four decades, the medical world has recognized the urgency of assessing suffering in patients, emphasizing the possibility of relieving it by daring, following Cassell [1,2], to discuss it directly with patients. At the same time, despite this claim and the work on pain-related suffering by Price [3], Wade [4], Büchi., *et al.* [5], no golden rule has been established to define suffering. In addition, end-of-life suffering, especially in palliative care, has ruled out patients with chronic conditions and in particular those with chronic pain whose suffering is part of everyday life. In this context, it seems not only necessary to provide a theoretical overview, but to equally discuss a working tool that could systematically assess suffering and thus fill an important gap of our time. Science and medicine are turning more and more towards specificity, offering genetic profiles, neurobiological pathways, knowledge on mechanisms and molecules that allow a personalized diagnosis and care. But avoiding the systematic assessment of disease-related suffering prevents us from having a holistic

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view of the patient's condition. For Cassell, "the canons of science that have held medicine in thrall for much of the twentieth century do not have a place for the phenomenon of suffering" ([2], 276). The failure of diagnosis and thus of the treatment of suffering does not only come from the increasing use of technology, from the emotional boundary that caregivers impose on themselves with patients ("the requirement of parsimony" as coined by the French psychiatrist Jean-Jacques Kress; Ricœur [6], 69) or caregivers' ignorance of their own subjectivity and personal suffering, their "feelings, intuition, and even the input of their senses - that would be necessary to detect suffering in their patients" ([2], 276). For Cassell, "the fact that suffering, like pain, is subjective and cannot be measured may be an important reason" ([2], 276). It could even be the main reason.

My disagreement lies with this last crucial point, since assessing human suffering is all but impossible. Clearly, diagnosing suffering by health professionals is difficult in the absence of appropriate means. But addressing the main issues attached to the evaluation of patients' suffering, both conceptual and methodological, allows to equally nourish the development of its assessment tool. A simple and effective clinical tool to evaluate the degree of suffering related to pain as well as to illnesses in general and to characterize its specific nature in each patient, would favor a finer diagnosis and a more individualized management of chronic patients.

Terminal suffering and persistent ongoing suffering

Wanting to analyze suffering and integrate it into a standard clinical assessment of the patient requires first of all to shed light on the relation that this universal and common human experience has with pain. This first step, which we already successfully tested in the laboratory [31,34,65,66], is necessary to provide a solid foundation for including suffering in the well-established pain protocols at the clinic. Traditionally, experimental and clinical measurement of pain has focused on pain intensity and unpleasantness. But in order to identify the affective and cognitive load of pain that unpleasantness alone cannot mirror, it should be considered to involve the additional component of pain-related suffering. To capture the pain in all its magnitude, Melzack and Wall [7] refer to the official definition of the International Association for the Study of Pain arguing that "the problem we face is the word "unpleasant". The pain is, of course, unpleasant; but it is so much more. [...] what is missing in the word 'unpleasant' is the misery, anguish, desperation, and urgency that are part of some pain experiences". It is therefore remarkable that consensual theoretical classifications and clinical practice omit to include the associated suffering, preventing a real conceptual renewal of the notion of pain, and that in the light of recent years inflamed debates calling to update its official definition [67-70]. To avoid further amalgams both in science and medicine regarding suffering in general and in relation to pain requires to focus on: 1) identifying suffering at the end of life (palliative care, terminal diseases) versus persistent suffering (pain and chronic diseases); 2) being precise and distinguish between suffering in general and pain-related suffering; 3) renewing the consideration of suffering as an extended form of the pain's unpleasantness; 4) educating professionals not to confuse between suffering and pain.

The first challenge consists in accepting a definition of pain open to a three-dimensional paradigm with three main components, including suffering. Indeed, the advance in biomedical research since the 1960s led to the inclusion of the affective dimension of pain, beyond pure nociception and its mechanistic consideration as a sensory response to tissue damage [8]. The search for a more holistic view as well as ground experience led to the examination of the role of its associated suffering. What I name here the third component of pain-related suffering was already discussed from various angles in the literature following growing changes in medicine as demonstrated by the work of William K. Livingston, author of the classic Pain Mechanisms [9] and the book Pain and Suffering [10]. Despite the title of this pioneering book, suffering was not defined and only implicitly mentioned in the context of "the treatment of the problems of human pain" (218). Over the years, three recurrent waves in pain research have continued to raise the problem of suffering: in the 1980s [3,11-16], the 2000s [17-24] and since 2010 [25-31,34]. This increasingly renewed interest seems to be motivated by the willingness of researchers and health professionals to relieve not only the pain, but also the suffering resulting from its negative impact on patients' lives. Yet studies on the subject remain marginal and inconclusive. Other than palliative care focusing on terminal suffering [28], this aspect has not been systematically examined in the clinical context and no validated measure or direct estimation methods exist to date for assessing ongoing persistent suffering associated with chronic pain and other chronic conditions.

One of the major issues is the difference in nature between the types of suffering since when related to long-term pathologies, such as chronic pain, suffering expresses harmfulness to the person without constituting a vital threat to their life. Care management has been developed in order to reduce the unnecessary suffering of dying patients, leading to the development of strategies and means to assess terminal suffering with ethical guidelines helping physicians balance between their medical obligations and the relief of patients' agony [35]. But while the need for patient relief is always present, it implies "appeasement" for terminal suffering and rather reflects the attenuation of a continually tortuous but non-lethal condition for persistent suffering that is part of everyday life. Terminal suffering requires dealing with the fatal decline and the finality of death. Persistent suffering requires handling fluctuating states of a permanent illness, potentially lasting for decades, posing a threat not to life but to quality of life and well-being. It is therefore necessary to associate the pathology with the appropriate form of suffering so that it reflects its torment reliably.

Another problem concerns the frequent assumption in the literature that any form of suffering evoked must necessarily correspond to that of pain. One recent review examining the prevalence of suffering in various groups of patients, and more particularly in acute and chronic pain populations, demonstrates the widespread reference to suffering stating that "the terms pain, acute pain, chronic pain, and CPP's [patients with chronic pain] were exploded with suffering" [36]. However, by taking inspiration from clinical [2,27,37-40] or philosophical [32,41-43] models recognizing the multidimensional nature of suffering, it becomes clear that its presence in our life exceeds the context of pain and that the vast and complex concept of suffering in general goes beyond that of pain-related suffering. In other words, "suffering encompasses pain, but is not limited to it" [35]. It is therefore important to keep in mind that the patient might not report to suffering in their complaint over the pain, not because they do not experience it but rather because they conceptually associate suffering with bigger causes such as loss, traumatic events (war, survival, abuse), the threat of death (palliative care) or even in reference to earlier more aggravated medical episodes involving pain. Reducing the general notion of "suffering" to the specific reference of "pain-related suffering" seems therefore essential for not missing out on the contextualization and the interpretation of its precise nature during a clinical evaluation of the pain reported. To account for this variability, we are led to ask: how can we integrate pain and suffering into a single applicable model in order to be able to assess their interchangeable yet distinct role in the patient's experience of their illness?

Not confusing suffering with pain

Regarding the association between suffering and pain in acute or chronic pain conditions but also more generally, the literature attributes their overlap to "ordinary language: we speak of pain regarding the loss of a friend, but we report suffering from a toothache" ([6]. 59) and possibly to a real conceptual inability to separate them since suffering is identified with harmful circumstances of all kinds (painfulness). Emphasis on their differentiation often results in a widespread but legally viable dualistic categorization [47], attributing pain to the physical and suffering to the mental. In order not to fall back into this fallacious dualism of mind-body, since both pain and suffering manifest on both levels, the publications that follow Fordyce's historic call to avoid the frequent confounding between suffering and pain [15] led to a tacit agreement in the field of pain not to amalgamate and rather treat them as two distinct phenomena [2,20,27,48,49].

However, in examining the decoupling of suffering and pain while determining their "internal relationship", it seems that their frequent interchangeability in addition to the lack of a golden rule and consensual definition of pain-related suffering in both the professional and clinical literature [50] may be responsible for maintaining their confusion. In the review of Fishbain and colleagues, among the synonyms used in 740 referenced publications talking about suffering, the most frequently used terms are: "mental pain," "psychological pain," "mental defeat" and "existential suffering". This reflects the lack of specificity regarding the notion of suffering and a frequent mixture in various scientific disciplines between the two terms [36]. Besides the field of pain, we notice the confounding in neuroscience (identifying suffering with "social pain", [51,52]), psychology (identifying suffering with "psychological pain" [53]), suicidology and psychiatry (identifying suffering with "mental pain" [54-56] or "moral pain" used as the classic description of melancholic depression). In the context of hospice clinical practice, the palliative care pioneer Cicely Saunders introduced the term "total pain" to encompass the physical, mental,

social and spiritual components of pain and to address suffering [57-60]. Greater effort and communication between the different disciplines are therefore needed to avoid the continual overlap between pain and suffering.

This confusion and lack of clarity on their relationship becomes even more poignant with the growing impact of genetics, taking an opposite direction by dissociating the two. From a purely genetic point of view, this split aims to isolate and thus study each phenomenon on its own account. In a debate at Harvard dedicated to pain Arthur Kleinman, the founder of the field of social suffering, refused the promise of an absolute dissociation between suffering and pain taken for two totally independent configurations: "It seems to me that this is the great tension in our time. We are obviously living in the great age of molecular biology; [...] From Woolf we heard very explicitly that molecular biologists are defining pathways, receptors, and molecules that will separate the "pain" from the "suffering". [...] When we obtain knowledge like that, what kind of knowledge will we have? We have a knowledge of mechanism that's extraordinarily powerful and may lead to a new generation of drugs that will change the nature of the human condition vis-à-vis pain. At the same time we are going to continue to have human experiences that simply don't accommodate themselves to that sort of separation into suffering and pain as two distinct things" [61]. From the point of view of the human sciences, suffering is an intrinsic part of the person and consequently of the damaged feeling of the dying body. The clinical work dedicated to the cure and the relief of the ill person and not only to the sick body, shows that this is a problem caused not by a mere terminological imprecision or an intellectual negligence resulting in a dualistic simplification between the pain of the body and the suffering of the spirit. The problem lies in the inability to determine the precise interaction of these two independent phenomena that are intrinsically linked.

Pain-related suffering is the third component of pain

The failure to represent pain-related suffering can be attributed in large part to methodological difficulties. Classically, the scoring of the two parameters shaped the measurement of psychophysical responses to pain, particularly following the introduction in the 1980s of the multidimensional concept in pain [12]. Clark and colleagues were the first to challenge Goldscheider's theory of intensity, which advocated a unique sensory modality and thus a single dimension of pain by asking subjects to make judgments of similarity of pairs of stimuli ranging from zero to one hundred. Their study revealed a two-dimensional stimulus space, with a primary dimension attributed to the intensity of the stimulation and a second dimension referring to emotional aspects related to pain stimuli. In a later study, these researchers compared healthy subjects to patients with chronic pain, again revealing different constitutive dimensions of pain. The intensity dimension was the most dominant in patients, whereas the affective dimension was more prominent in healthy subjects (controls) [13,14]. Their method of analysis (multidimensional scaling) to identify the different dimensions of the perception of pain, based solely on the assessments of the subjects, allowed to identify the main parameters related to the sensory aspects of the pain (intensity) and those related to the affective aspects of pain (unpleasantness) while revealing the presence of another dimension regarding the "unbearable" nature of pain, thus preparing the ground for including the subjective space of suffering. However, because of the methodological difficulties (ambiguous results), this approach was not further investigated, and certainly not in the necessary global way to evoke a three-dimensional solution of pain that includes the concept of suffering.

To study this aspect, it has become crucial in our laboratory work to introduce the third parameter of pain into the pain assessment model by examining a three-dimensional paradigm based on the visual analogue scale (VAS) detecting Intensity (I) - Unpleasantness (U) - and pain-related suffering (PS) scores in response to four types of pain stimuli. The emergence of suffering in spite of the ethical restrictions of experimentation and the participation of young healthy volunteers demonstrate that suffering is not necessarily an attribute of pain perceived based on the model of the disease, as often stipulated [15], but is first and foremost an important feature of pure pain. The distinction made by the participants between unpleasantness and suffering shows that suffering is not a mere continuum of this primary emotional dimension of pain and that, although strongly correlated, the uncomfortable sensation of pain does not equate to the strong negative impact that gives rise to suffering. The qualitative results, collected during the semi-structured interviews and the questionnaires, also confirmed a precise meaning and a very distinct qualification, attributed to the perception of each of the three

components [44]. These studies have validated scales that assess pain in the context of experimental pain [31,34], demonstrating that suffering is an inherent factor in the experience of pure pain and an independent component that must be added to the two parameters currently used. The emphasis thus placed on the fact that pain intensity, unpleasantness, and pain-related suffering assess three different aspects of the pain experience, calls for the introduction of a three-component (three-dimensional) paradigm in the clinical context as well. Application of this account outside of the artificial and well protected environment of the laboratory where the experimental device can be manipulated to change the degree and type of pain induced, allows to identify the multitude of interactions related to personal, social, psychological and physiological factors that in many ways determine the expression of pain and suffering in chronic patients who are unable to act on the source of pain.

The inclusion of pain-related suffering based on empirical results allows for a better understanding of its role as an additional component that can no longer be reduced to a limited number of negative emotions as suggested by the assessment methods currently used. One of the aspects of its identification as an integrable but independent component of pain that is not simply an expansion of unpleasantness, rejects the two current most referenced modalities: either a suffering admitted as a simple extension - more intense, more severe - of pain unpleasantness, named a "secondary affective state" or "secondary unpleasantness" [19] with long-term implications of the pain associated with threat, loss and imminent damage to self; or else a suffering recognized for its independent register but reduced to the display of several distinctive negative emotions (fear, anger, frustration, anxiety and depression) [16-18] often occurring in persistent pain conditions [3,21,22,25]. The passage from a two-dimensional model to a three-dimensional model makes it possible to regard suffering as a self-contained component that constitutes a register with multiple variances that we can evaluate all together. Pain-related suffering is not just a few privileged emotions but an umbrella phenomenon that is not limited to catastrophism, depression or anxiety. Pain-related suffering expresses an increased emotional and cognitive burden that the unpleasantness of the painful sensation cannot sufficiently reflect, revealing its "unbearable", "unsustainable" [13,14], "threatening" [2] character, often associated with "misery", "anxiety", "despair" [7], "handicap" [45,46] and profound hurting.

Measuring pain related to chronic pain

In evaluting the place of suffering in the painful experience, it is not enough to recognize the four main amalgams discussed so far to then invest in a three-dimensional model that integrates suffering into the pain measurement system. Conclusive theoretical reasoning is insufficient in the absence of a validated simple suffering diagnostic tool for clinical use allowing to operationalize an established daily practice for consistently and accurately diagnosing pain-related suffering in large patient cohorts. One of the challenges comes from a recurrent phenomenon in a number of chronic pain patients that are already followed by pain physicians and who sustainably report pain of maximal intensity (up to 10/10), theoretically corresponding to "the worst pain imaginable". However, it is likely that this type of rating is more reflective of the suffering associated with chronic pain rather than its intensity. But without a systematic assessment of the degree of each component distinctively, it is difficult to determine what constitutes the disease, chronic pain, and what mirrors its negative impact on the patient's life, as a reflection of the disease-related suffering. A systematic assessment of suffering can therefore have a clear impact on the patient's management. In particular, its evaluation could help to explain the two emblematic categories: those for whom the intensity of the pain remains high but who claim not to suffer and those who continue to suffer despite a successful treatment reducing the intensity of the pain. I observed a third category, rather masculine, corresponding to patients who communicate little about their pain-related suffering, accumulating the harmful consequences both in regard to the disease and the management of their private-professional lives.

Currently, pain patients are asked to rate their pain level using a numerical scale ranging from 0 (no pain) to 10 (worst pain imaginable) and describe their experience using adjectives such as "stabbing", "drilling", "wrenching", "troublesome", "penetrating", "heartbreaking", "agonizing", "cruel", "punishing" (see for example the McGill Pain Questionnaire [62]). These scales help to communicate and quantify the subjective experience of pain. However, even though these questionnaires have been able to evaluate several dimensions of pain

(sensori-discriminative, affective-emotional, cognitive for McGill, sensory dimensions of neuropathic pain for the NPQ [63]), they remain insufficient because they are very technical, do not provide a complete vision of the emotional and mental states and almost no information on the negative impact of the pain causing the suffering.

This approach consists in providing patients with a set of questionnaires to study the impact of pain on various psychological parameters, functioning and quality of life. This amounts to analyzing the suffering through the prism of an agglomeration of the associated emotional or cognitive negative states with which suffering is often confused, and functional aspects such as the diminution of the quality of life or a resulting disability often used as an evaluation criterion to describe suffering, instead of changing strategy and directly exploring the configuration of suffering in a patient at all levels. The suggested change consists in analyzing the suffering through the examination of the negative impact of the disease using both direct and indirect estimation methods investigating the different levels and types of suffering and not only the psychological or functional properties that are wrongly estimated to fully reflect it [71].

However, in extending conceptual understanding to the practice of assessing suffering, the emergence of philosophical inquiries undermines its evaluation by the use of simple scales: human suffering is a vast and complex experience, how to measure such a diffuse and variable constant? Moreover, given the dual nature of suffering that cannot be reduced to a single essence but can either manifest as a transient feeling (a separation, a cured illness) or an existential condition (the loss of a child, a chronic condition), what does the measure refers to if we are not evaluating something but rather a lived experience? The practical outcome of this measurement tool cannot therefore be asserted without taking into account the fact that suffering is a phenomenon of dual nature that manifests itself either as a feeling or as a symptomatic persistent condition [31-33,42,43,64].

The validation of a new tool seeks to determine the degree of suffering related to pain and to characterize more precisely its different dimensions in each patient. This process consists in verifying the existence and the possibility of evaluating five dimensions constituting the suffering (physical, emotional, cognitive, social, existential), independent of the sensory and affective components of the pain. The criterion of judgment is thus focused on the evaluation of the different dimensions of the lived experience of suffering thus defined by means of numerical scales and visual tools. And as my fan models demonstrate [71], suffering as well as pain is a complex concept that does not depend on a single criterion, but consists of several different dimensions that need to be assessed in order to determine which dominant aspects are the most painful. In this sense, physical suffering refers to the bodily experience of a pain that is experienced as too intense and intolerable, as well as functional impairment or disability caused by the disease. Emotional suffering reflects the patient's affective reaction to the "too much" that weighs and inhabits them, to the heavy load that can no longer be endured and which is expressed by emotions often associated with aggression and anger in chronic pain. Mental suffering is the cognitive response to the distressing burden saturating the mind by causing mental fatigue, with reduced capacity for attention, concentration, memory, or the ability to employ cognitive strategies allowing to adapt to the situation. Existential suffering refers both to malaise and continued overwhelm which has become second nature, as in the case of chronicity but also the loss of a loved one or of trauma raising questions regarding the meaning a person attaches to their life. Social suffering refers to the effect of pain on our relationships with others, stipulated more precisely by the impression of being misunderstood, ignored or isolated.

Conclusion

A representational assessment tool of measurement of suffering in chronicity may allow to treat suffering at different levels of experience, thus make secondary the need to identify the thing in itself, the essence of what makes us suffer, allowing to preserve the diversity of criteria that compose a suffering state but also the displacement between these two natures. Indeed, the different dimensions can reflect both episodic suffering (feeling) or lasting suffering that dominates the whole existence of a person (condition) in chronicity. In this sense, a person may experience suffering as a passing, transient feeling that has come to an end when the illness has been cured, but may also experience a situation of limitless distress, such as the loss of a child or an incurable disease, making their torment the basis of a continu-

ous reality. The announcement of a curable cancer causes episodic suffering that could be transformed into permanent pain (duller, but no less tortuous) accompanying the person each day following the appearance of chronic pain. For a constructive model of the suffering experience in patients, we must keep in mind the very possibility that a transient feeling transformed into a way of life can sharpen the growing sense of helplessness in the face of pain, a fate with which it is very difficult to reconcile. The two natures of same phenomenon of suffering must therefore be taken into consideration when approaching a patient or even a volunteer in a study of experimental pain, because the comings and goings between the two facets of what is simply called "suffering" could better explain their "exaggerated" reaction, especially when expecting to find a cure and realizing that the pain is there to stay. Importantly, what is ultimately measured is not a "thing in itself", a well-targeted enemy to subdue but a fluctuating lived experience that oscillates continuously between different dimensions of suffering. Thus, a context-sensitive and clinically validated method may allow physicians to follow the evolution of the patient in chronicity by having a clear picture of the various dimensions of suffering, and distinguishing between what amounts to their pain ("the disease") and what consequently results from their suffering. Tested on large cohorts of patients, this tool for diagnosing pain-related suffering could possibly explain the innumerable variations in a patient's response to a recurrent disease, interindividual differences in responses to a similar condition, and how the different types of chronic pain syndromes (such as fibromyalgia, neuropathic pain and nociceptive pain) play a prominent role in the manifestation of suffering.

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