Chapter 7
A Scientific and Philosophical Analysis of Meanings of Pain in Studies of Pain and Suffering

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Abstract Carefully weighing three major constraints for elucidating pain and pain-related suffering, I argue that the study of their meanings in experimental and clinical research is necessary. This research program can further the understanding of pain self-report observable pain behavior in addition to physiological signals of pain, thus combining subjective and objective measures for better assessing the pain experience. Much of the information is derived from the encountered difficulties during the ongoing development of pain and related suffering questionnaires, in both the laboratory context conducting experimental studies with healthy volunteers and in the clinic with chronic pain patients. The chapter exposes the challenges of meaning acquisition while proposing, following Eric Cassell, that the study of pain recognizes both objective and personal meaning types. The chapter also explains why the ambition of science to obtain an exhaustive picture of pain is impossible, and that a continuous revision of pain meanings is necessary, especially for clinical studies of chronic pain patients. The methodological dilemma however remains, whether a direct approach is the most appropriate for understanding the state of the patient or is it rather an indirect gathering of information that may best depict individual pain and suffering.

Keywords Pain · Suffering · Meaning acquisition · Experimental studies · Chronic pain · Clinical studies · Questionnaire · Dilemma · Direct or indirect approaches

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S. van Rysewyk (ed.), *Meanings of Pain*,
DOI 10.1007/978-3-319-49022-9_7

1 A Scientific and Philosophical Analysis of Meanings

If there is a difficulty that keeps emerging regarding pain, it is in recognizing the lived experience of a seemingly invisible condition. For patients, this can cause difficulties in communicating as well as elucidating and diagnosing pain, all set against the risk of disbelief. Detecting the concealed is even more challenging in patients with chronic pain, whose pain extends over months and years, since it is not uncommon for these patients to report high levels of pain (8–10 out of 10) for long periods despite understanding that the value 10 represents "the highest pain imaginable". Sitting across from chronic patients who I interviewed regarding their pain and related suffering, it was striking to find no tangible, apparent, physical expression to match the elevated scores and the descriptions of a torturous internal state owing to persistent nociception ("I am an invisible invalid", a patient told me). Pain, unlike many other diseases and conditions, does not always have a demonstrable physical proof to attest for its etiology. Pain therefore obliges therefore obliges caregivers to turn to patients' subjective narrations in order to reach a valid objective inference in addition to their knowledge of important preconditions known to trigger pain (post-surgical pain, post-stroke pain, chemotherapy induced painful neuropathies). Such dissociation between the unobservable but strongly felt illustrates the paradox of pain—that of *objectively attesting to a torturous condition without apparent evidence*—and the consequent necessity to rely on subjective self-report measures for ascertaining a diagnosis which lacks biomedical proof. Flor and Turk note in this respect that "in significant number of people reporting back pain, fibromyalgia syndrome (FMS), and headaches, among other prevalent conditions, no physical pathology can be objectively verified, despite advances in imaging techniques" (2011, p. 6) (Carragee and Hannibal 2004).

In the absence of an identifiable cause or external physical signs, the phenomenon of pain challenges the idea that objectivity in medical judgments must necessarily be based on empirical facts. A great deal of research in the clinic and in the disciplines of science and philosophy has therefore been devoted to the question of subjectivity of pains (Coakley and Shelemay 2007). Furthermore, the challenge involved in deciphering these private states is not only conceptual. It has crucial practical impact on the eventual distrust of third parties such as insurers and employers seeking reliable justifications and most importantly, on misinterpretation of symptoms due to medically unexplained pain conditions. The need for objective information to understand an elusive but undeniably excruciating reality led to an abundance of pain assessment methods (Turk and Melzack 2011). Among them, as we are about to see, are methods based on the observational-behavioral perspective, proposing a solution to the problem of understanding pain, and a recent perspective revaluating what is subjective and objective in pain thus proposing a shift in the way we conceive the problem.

When seeking accordance between external signs and internal conditions, one classical reference that initiated much research on pain responses is the behavioral perspective. Forty years ago, Fordyce's behavioral approach to studying pain suggested changing the focus from subjective states to behavioral and thus observable manifestations of pain (Fordyce 1976; Main et al. 2015). Fordyce and colleagues were pioneers in applying the operant conditioning paradigm to chronic pain, leading to an important body of investigations that had a significant impact on the field (Sanders 2002). Essentially, operant conditioning proposes that behaviors are largely determined by their consequences and interactions with the surroundings. Applied to pain, observable conducts, including emotional responses, are thought to communicate a person's abnormal distress state and suffering (e.g. nonverbal responses like moaning or grimacing, verbal responses like complaint, frequency of medication intake or therapy and activity level compatible with pain such as sitting down or rest). It is important to note that operant conditioning is not purposeful, but is characterized by the fact that much of it is nonconscious or implicit, i.e. not consciously known to the patient or to an external observer. Thus, learnt behaviour is usually not shown to obtain a goal or a predetermined result but is the consequence of inadvertent learning (Becker et al. 2008, 2011, 2012). Overall, this approach has proven to be very effective in the rehabilitation of chronic patients and the reduction of their medication dependency thanks to the identification of specific behaviors and a tailored adaption of positive/negative reinforcements (Flor and Turk 2011, p. 399–410).

However, to what extent reinforcement contingencies control pain can only be determined in a careful behavioral analysis, which is the basis of behavioral treatments. Limitations come from assuming that maladaptive behaviour, which originates in acute pain, persist after the nociception is gone due to environmental rewards such as increased attention, care and legitimately reduced responsibilities. Describing observable relations that positively or negatively reinforce pain behaviors is believed to reflect a faithful picture of the hidden world of the pained. And yet, a sequential analysis of operant or non operant responses, as a basis for diagnosing the extent of pain and related-suffering without directly asking the patient for their reasons to engage in such behaviors, may be misleading (Flor and Turk 2011, p. 8, 61–67). Rest, for example, may not necessarily convey a desire to gain spouse or social empathy (Flor et al. 1987; Lousberg et al. 1992; Romano et al. 1992), but rather reflect a strategy for avoiding the undesired peak of paralysing pain. Behavioral observations, as objective measures, assuming to report the sense of a subjective experience could therefore lead to pseudo-explanations. This is because inferences may be based on performances and functional assessments and not enough on introspection on pain, as revealed through patient narratives and stories.

Several years later, Keefe and Block (1982) published their behavioral observation system, considered as the most systematic attempt to provide a pain behavior checklist. The reliability of the behavioral approach was demonstrated through a correlation between the subjective pain ratings and the observed pain conducts of the patients (Keefe et al. 1987). Paradoxically, this shows that the basis for pain detections remains patient-self report (Flor and Turk 2011, p. 238). This stance echoes similar conclusions in studies of subjective pain and imaging (Coghill et al. 2003). In addition, since no "third-person" observer can accurately and entirely know the pain of another and in the absence of an objective "gold standard" for a systematic study of pain and related suffering, the utility of "first-person", subjective, reports received support.

Following the requirement for objectivity in deciphering pain, a more recent attitude calls for a shift in perspective. The philosophical debate between "perceptual" and "representationalist" (Michael Tye) theories of pain, to which an entire book of essays was dedicated (Aydede 2005), led to conclusive suggestions by the scientist Donald D. Price and the philosopher Murat Aydede to treat "first-person" subjective reports as a form of objective knowledge. Price and Aydede claim that introspection ("first-person" approach) is not "scientifically and methodologically suspect" and should be integrated into the standard objective ("third-person" observer) practice (2005, p. 243). In associating individual descriptions with experimental patterns, the explanatory power of "first-person" reports is viable since it obeys the same scientific procedure of approving/rejecting initial hypothesis based on results, of finding common factors when encoding the specific pain descriptors and of comparing their interindividual differences. This experiential method, which the authors describe as phenomenological (reports of immediate experiences in the present-tense), is said to propose hypotheses that provide a basis for defining the pain and a practical outcome that can be tested using quantitative tools.

My aim, however, is not to advocate either perspective or even a different alternative since my philosophical-scientific-clinical work on pain and suffering brought me to the conclusion that their elucidation and assessment clearly necessitate combining subjective and objective approaches. These are aspects of pain with no one superior to the other. To the difficulties so far pointed out, I would add that the persistent desire to find a reliable objective anchor for their evaluation is vain without the benefit of "first-person" experience. Pain report and observable pain behavior in addition to physiological signals of pain define what pain is. But in this respect, what is currently missing to complete the picture is not only a clear idea of how people perceive and then communicate their pain (directly or through others observing them), but explicitly stating what it means to them. This chapter therefore proposes to *model pain and related suffering with the inclusion of meanings and personal concepts*, thus extending the literature in a direction that further integrates the *individual life world* into the standard, objective, approach. Much of the information presented in this chapter comes from difficulties pain patients encounter during the development of pain-related suffering questionnaires, in both the laboratory context with healthy volunteers, and in the clinic with chronic pain patients.

Regarding the notions of pain and suffering, they are drawn from our three-dimensional approach to pain measurement based on validated psychophysical research (Bustan et al. 2015; Brunner et al. 2017; Löffler et al. 2017). Traditionally, pain has been viewed as containing two dimensions, a sensory-discriminative (intensity) and an affective-motivational dimensions (unpleasantness). Considering that pain involves higher-order emotional and cognitive processes that go beyond unpleasantness, we extended the assessment of pain by introducing an additional dimension of "pain-related suffering". Suffering is a fundamental constituent of pain (Loeser 1980) and should therefore be included in clinical pain assessment, where pain and suffering are often confounded (Fordyce 1988; Fishbain et al. 2015). In addition to showing that we can measure the three pain dimensions, we conducted a qualitative study to examine the meaning participants attribute to "Intensity", "Unpleasantness" and "Suffering" (Bustan et al. under review). What I therefore refer to in this chapter is only the form of suffering yielded from, or in relation to, pain.

Almost thirty years ago, Clark, Janal and Carroll wrote: "The question 'What is pain?' is often answered, 'Pain is anything the patient says it is'. This is an extreme view, but if we could quantify such broad statements, we might be able to understand what the patient means" (Clark et al. 1989). To quantify is also to qualify by looking at the meanings attributed to numerically rated pain and suffering, as they did. Regarding suffering, taken here as a derivative mode of pain and not as the general multifaceted construct, it could be said that it reflects all the negative aspects in life related to the pain experience, even though conceptually the notion extends beyond pain per se and is more complex. In my philosophical theory on pain and suffering, the origin of the difficulty in obtaining a complete picture of the sufferer is assumed not to be only methodological, and cannot be resolved by using a better scaling system for determining and communicating one's pain intensity or distress signals. The difficulty lies, on the one hand, in the *evasive and invisible* nature of pain and suffering, and on the other hand, in the complex intersection between *the inner*, private, *world of the sufferer* and his *outer*—interrelational, social and cultural—*world*. Following these complex and multi-facetted percepts, we come to realize that pain is not only an unpleasant sensory, but also an emotional experience (Melzack and Casey 1968), and that suffering is a double-natured phenomenon, which expresses itself either as a *feeling* or as a prolonged *condition* (Bustan 2015, 2016). In this sense, a person may experience suffering as a passing *feeling* that will come to an end, but he or she may also experience a situation of endless affliction, such as the loss of a child or a chronic pain *condition* in the case of an incurable disease, making one's torment the basis of an everlasting reality. In my philosophical work (Fan Model), I define this last and fourth dimension as existential suffering, following the three other dimensions of physical, emotional or mental-cognitive suffering. Overall, my call for reviving the account of meaning guides four questions gathered together to lead the general inquiry and it is important to keep them in mind when reading this chapter: What is named by pain and suffering? How is pain and suffering best assessed? What is the contribution of meaning acquisition to the process of understanding pain and suffering? What is the benefit for the patients of pain assessment that includes meaning elucidations? These questions are addressed in turn below.

2 The Three Constraints in Meaning Acquisition of Pain and Suffering

In the medical and scientific literature, pain patients appear under numerous different designations. Their division into subgroups and the classification of their condition according to a consensually validated set of criteria assembling each of the relevant aspects—medical/physiological, psychosocial, and behavioral—provide a specific profile that labels and thus recognizes their plight (Merskey 1986; Turk and Rudy 1987; Williams and Keefe 1991). Such classifications appeal to the explanatory power of an established, rigorous scientific approach. At the same time, these in-depth classifications risk remaining inaccurate as long as they neglect to describe the meanings every individual attributes to his *own* pain and suffering experiences (Williams and Thorn 1989). What one conceives as imperfect may look impeccable to another, and seemingly, a person can qualify as tolerable the pain of a chronic syndrome his fellow might consider as excessive to the point of having prominent thoughts about death. The difference in appreciation lays in the sense the illness has acquired for each individual. In patients who view their chronic pain as a form of great injustice ("What have I done to deserve this?"), suffering is enhanced and so is the despair, creating possible resistance to various forms of treatment (Sullivan et al. 2008, 2012). Without identifying these subjective meanings, physicians cannot access the heart of the problem and apply non-invasive clinical procedures such as hypnotic analgesia (Erickson 1967; Barber 1996; Benhaiem 2006; Jensen 2011) biofeedback, neurofeedback, mindfulness or guided imagery, teaching patients to change the way they think and feel about their pain (Butler and Moseley 2013; Louw and Puentedura 2013). I tend to think that since the nature of the pain meaning is a central issue in clinical practices attempting to modulate individual pain perceptions, there are also gains to be made during routine pain examinations for personalizing treatment based on the recognition of the specific distress it involves (fear, sense of threat, loss of control, anguish, disruption, helplessness, incompetence, and so on).

Studying the meaning an individual attributes to his own pain experience could help adapt the right medication and potentially reduce drug intake in a patient. The identification of the negative component associated with the pain may facilitate targeting the right resources available for confronting it. For example, a sense of loss for *phantom* limb pain shifting into a favorable regained sense of control, may provide relief and reduced nociception that coincides with medication reduction. It is *a conceptual reorganization using meaning*, comparable to the perceptual reorganization occurring in the human brain as suggested by Ramachandran and Hirstein with the mirror box, where the mirror projecting the existing hand creates the illusion that the amputated hand has been returned (1998). Several studies confirm a reduction of phantom limb pain using the mirror treatment (Chan et al. 2007), although other studies have found no evidence for change (Brodie et al. 2007), However, the procedure seems to re-establish a sense of personal control over the phantom limb (Flor and Turk 2011, p. 513). Similarly, as my colleague Dr. Jean-Marc Benhaiem proposes in his hypnotic practice, in encouraging the patient to become aware of the sense he attributes to his pain, the patient can be engaged in thinking that his amputated leg is not a *loss* but simply an earlier *restitution* of a part of the body that would anyway be given back when the time comes. A change in the meaning associated with the vivid sensation of the missing limb when moving from loss to restitution can attenuate the sense of deprivation and facilitate the phase of mourning, so essential for better coping with the pain experience.

Looking back, the concept of meaning appears in the pain literature from its very early days. In his seminal work, anesthesiologist Henry Beecher emphasized the relation between the meaning of the wound and the pain experienced in war casualties, demonstrating that "the intensity of suffering is largely determined by what the pain means to the patient" (1956). The field indeed followed up with several standardized methods categorizing the various pain meanings, as with the display of pain descriptors in the McGill Pain Questionnaire estimating the quality and intensity of the pain experienced (Mehack and Torgerson 1971; Melzack 1975), or with the measurement procedure employing the Multi-Dimensional Scaling (MDS) (Clark et al. 1989). The field recognized the need to acknowledge the influence of meanings for understanding patients (Morris 1991, 2010, 2011; Arntz and Claassens 2004; Price and Barrell 2012; Thacker and Moseley 2012). However, this inquiry was not consistently integrated into the operant management of pain. The various MDS models, for example, were based on the idea that individual differences are important and can be structured mathematically to expose the individual perspectives yielded in verbal descriptors about pain and suffering. These procedures had methodological limitations that did not allow the capture of all the aspects, in particular those reflecting excruciating and unbearable pain. As mentioned earlier, we recently validated these more enhanced aspects under the third measurable dimension of pain-related suffering after having demonstrated that both pain and suffering are objectively measurable phenomena. At the same time, I have reason to believe that the challenge of analysing pain meanings is not only methodological and cannot resolve by using one global approach to uncover the overall descriptors of global pain in individual patients. Several issues bear on the topic.

3 The Inexhaustible Account of Meanings

One issue concerns the misleading ambition to obtain an exhaustive picture of pain without considering its manifold representations. This consideration requires a continuous revision of emerging meanings, either due to multi-dimensional profile of pain or, to the fact that the perception of pain evolves depending on its application within a context and in a given time frame (Moseley and Arntz 2007). We can assess pain, but not completely, getting closer and closer to it, by unravelling its transitory meanings without expecting, however, to obtain a finite list of qualifiers. In this respect, the program of identifying utterances in an exhaustive and finite way is doomed to fail because "meanings", as the American philosopher Hilary Putnam says, “are not objects in a museum” (1988, p. 119). The meaning of a concept may evolve as time passes by, so even though the term maintains an identity that carries on a core invariant (allowing to identify pain as being pain), its representations are not necessarily identical, stored as locked forms, but accumulate insights that add new layers to the former conceptual attributions. Putnam speaks, in this respect, of “enough continuity” that is kept “through change”, explaining the elasticity of a significance undergoing transformations by arguing that “meanings have an identity through time but no essence” (p. 11). The meaning of pain is therefore never fixed. Moreover, the challenge in assessing pain consists in finding a way to process the modulations of the meanings associated with this lived phenomenon. This is particularly relevant to conditions becoming chronic because in these circumstances, pain is often first thought of as a burden requiring strength and adaptable coping strategies on the way to recovery, before turning into a permanent condition representing a forever lasting, defeating threat.

The other alternative found in existing paradigms to this all-encompassing classification plan, consists in proposing a reductive account of pain meanings composed of *fundamental* features. But here again, the principle reason why a finite list falls short of portraying pain remains. According to Price and Barrell, “although the particulars [of meanings] are likely to differ radically across chronic pain patients, it is likely that they experience at least a partial commonality of meanings. If that is true, then it should be possible to assess their presence and perhaps even measure their magnitudes. A scientific analysis of meanings in studies of pain and suffering would be helpful in this regard” (2012, p. 179). The ability to reflect on the relevant range of meanings touches upon the requirement to obtain a reliable picture of the pain experience based on a commonality of meanings or similarity judgments which assure that the information is consistent with other cases when passing from the personal (subjective) to the general and shared meaning (objective). But in further proposing, following Price and Barrell (2012), three underlying fundamental meanings associated with pain-related suffering (interruption of life activities, difficulty to endure and concern for the future), other significances that do not fit into this classification are discarded and lost.

In short, the problem with these two positions—the all-encompassing and the reductive—is not so much a matter of finding the proper method to faithfully compute all possible pain and suffering meanings. The problem is that the interpretation of pain and related-suffering has no purely formal or a priori knowledge of the pain qualifiers to rely upon. If we are to understand pain and suffering in order to clinically treat both, the standardized quest should admit to the conceptual pluralism of pain meanings within a formal semantic framework while equally accepting the emergence of *unexpected and contextually bound* meanings that no global structure can predict (Karoly and Jensen 2013, p. 5; Bustan et al. under review). A better understanding of the subjective or personal aspect of pain can lead to better treatment. This might seem obvious but the methodological challenge of formalizing such *intuitive matter* is considerable and can only be obtained by recognizing personal meanings according to their *actual use*. Philosophically, this approach follows a long tradition that began with Wittgenstein’s declaration in

Philosophical Investigations stating that 'meaning is use' (1953 §43, 61). This claim has become a rule of thumb for linguistics and analytic philosophers (Putnam 1988, p. 113–120), implying that the same phenomenon can be described in many different ways depending on how we employ the term that expresses it. We can interpret pain as either excruciating or pleasurable, following its context and form of occurrence (sexuality/torture/illness), which demonstrates the immense epistemological gap created by the possible uses of the same word. At first, this rule may seem dynamic enough for obtaining a formal system of meanings, integrating the variety of pain descriptors with the different uses coming together to forge a concept. Yet this idea of use does not convey a purely linguistic construction that could lead to an overall categorization based on the causal relations of sensory, affective and cognitive properties evoked in the patient's statements. For example, the semantic construction 'a person directing others and exercising a high degree of influence over them' refers to a leader and 'a flying animal that is also covered with feathers' to a bird. But, the descriptive statement "a sickening and miserable sensation of malaise" does not necessarily invoke or define pain even though it was computed as an item characterizing the second emotional dimension of pain (Clark et al. 1989).

When it comes to pain, the intuitive meaning of this private sensation obliges us to pay attention not only to "the practice of using it" in the language according to Wittgenstein (1966, p. 68), but also to its subjective account. Putnam explains that we no longer find with Wittgenstein a theory of causal relation of references (this is ascribed by that), with patterns that could facilitate, if I may add, the creation of a system of meanings to fit the enterprise of the scientific grid. He admits that "at one time, I myself had the hope that what Wittgenstein refers to as the use of words, or in this lecture as the technique of usage, could be completely surveyed and analyzed in a functionalist way; that is, that all the various referring uses of words could be neatly organized and depicted by something like a computer program" (1992, p. 166). Even with the flexible approach of meaning as use, a holistic or even functionalist account of meanings is not possible. The discussion, in fact, does not turn specifically around pain. Putnam rather speaks of interpreting private mysterious phenomena such as religious beliefs. He does not go into Wittgenstein's famous and very frequently cited view regarding the obviousness of knowing we are in pain, which makes the phenomenon certainly meaningful to the individual but often obscure to others who cannot share his internal sensations (Wittgenstein 1953, §303, 317, 350). Due to its intimate nature, Wittgenstein argues, pain is difficult to interpret with certainty and translate into a logically consistent proposition that is understood by all. At the same time, the phenomenon does take on meanings and could be pointed at through its linguistic practice. "You learned the *concept* 'pain' when you learned language", writes Wittgenstein (1953, §384), since having pain does not mean you acquire the concept of pain. It is necessary to pass through the mediation of using it in the language (public and shared, not a private one) to assure its understanding and communication.

Going back to the difficulty in obtaining the desired network of pain meanings because of its subjective and I would add intuitive character, Putnam demonstrates the novelty of this rule of thumb when assimilated to a game. Wittgenstein, he explains, "speaks of games as forming a family, as having a family resemblance, and he also uses the metaphor of a rope. The rope is made up of fibers, but there is no fiber running the length of the whole rope. There are similarities between one game and another, but there is no one similarity between all games" (1992, p. 167). In applying this key notion of family-resemblance, we may recognize different fibers (neuropathic, nerve or muscular pain conditions) running through the metaphoric rope of pain, revealing overlapping similarities (it is sore, it is excruciating) all referring to one single lived phenomenon. The meaning game therefore consists in looking for the resemblance uniting all the family members (the various pain conditions) while acknowledging their distinctive features (pinching, drilling, stabbing). This does not imply that the discrepancies in referring to pain are not real or true and should be disregarded in virtue of assembling similarities, but that altogether they form the concept of pain in an inexhaustible manner. None runs consistently through the full length of the rope. Expressing pain is therefore a never-ending game of perception and interpretation, where neither simply having it, nor inferring it from other sentences could assure a complete understanding of its evolving meaning.

4 The Dilemma: Enquiring Directly or Indirectly About a Patient's Pain and Suffering

Along the same line, a second controversial issue regards choosing an implicit versus explicit approach for obtaining the clearest indications of pain and suffering, while keeping a necessary distance in order to avoid eliciting irrelevant responses. This is precisely the difficulty we encountered in the course of our ongoing development of the pain-related suffering questionnaire for chronic pain patients, aimed at assessing the impact of pain on all aspects of life eliciting suffering. The questionnaire is particularly relevant here because, as I said earlier, the underlying premise of integrating suffering in pain evaluation assumes that it could encompass emotional and cognitive qualities of pain, which the two traditionally evaluated dimensions of intensity and unpleasantness do not fully embody. The conceptual scheme of this third dimension refers to strong meanings such as misery, desperation or urgency (Melzack and Wall 1983) that are constitutive parts of acute and chronic pain but which the other two dimensions cannot convey. Sullivan and Ballantyne offer a similar argument in a recent overview (2016), advocating that suffering is more related to the meaning of pain than to its intensity and should therefore be included in chronic pain assessment, thus giving rise to numerous reactions in a scientific-clinical world still very much taken by the practice of numerically measuring the single dimension of the pain intensity (Okkels et al. 2016).

In the process of developing a questionnaire, a basic requirement for data collection consists in avoiding any effect of the investigators on the patients' response to prevent biasing their pain and suffering behavior. Armed with this rule of method, the dilemma however remains, whether a direct approach is the most appropriate for understanding the state of the patient or is it rather an indirect gathering of information, as I am about to demonstrate, that may best represent individual pain and suffering. Eric Cassell, the American physician, has been leading a line of direct approach, "asking whether the patient is suffering and why. Even though patients often do not know that they are suffering, they must be questioned directly: 'are you suffering?' 'I know you have pain, but are there things that are even worse than just the pain?' 'Are you frightened by all this?' 'What exactly are you frightened of?' 'What do you worry (are afraid) is going to happen to you?' 'What is the worst thing about all this?' Once asked, patients have to be given the time to answer. The questions are purposely somewhat vague; they tell patients that they have permission to talk about things that usually no one wanted to hear before, and they do not specify what answers are expected" (1999). In his writings and especially in his canonical book *The Nature of Suffering and the Goals of Medicine* (1991), Cassell deplores the silence around the suffering of patients by doctors who feel uncomfortable asking these questions, unable to free themselves sufficiently for dealing flexibly with these concerns since they are afraid of lacking the capacity to provide the proper relief. His call for a change in attitude among physicians aims at recognizing the importance of personal expression and the meanings patients attribute to their experience so that caregivers can see the person behind the pain, beyond the physiologic mechanisms of the body or the disease (1991, p. xv).

However, clinicians who intentionally hold back from asking such direct questions consider that the best way to approach these sensitive matters is by loosening the bond between the pain condition and the consequent suffering. They claim that doctors are never disinterested by the patients' subjective experience and cannot maintain a cold look, remote from the obvious, apparent suffering. At the same time, directly asking a patient if he suffers is a mistake since the real challenge consists in trying to explore all the content and dimensions of suffering and its specificity for each person in order to detect particular patterns that the patient himself may not even consider. In addition, the risk of labeling what we seek to discover may inevitably lead the patient to respond to the questions in an inferred manner. An attitude that is discrediting and which adds up to deligitimizing pain patients who are often not taken seriously by non-pain specialists, thus developing a tendency to compromise the accuracy of their accounts in desperation for a diagnosis and a recognition of their pathology. Response bias in pain presentation is thus a complex matter (Robinson et al. 1997). There is always a hidden gain in a patient narrative, even unintentional. Bringing us back to Beecher, who observed, in his work at the Anzio Beachhead during the Second World War and at the Massachusetts General Hospital, the difference of the meaning severely wounded soldiers attached to their wound and concomitant pain sensations compared with postsurgical patients clearly stemmed from its relation to a potential evacuation from the battle field (1956). To settle the risk of resulting bias inducing a spectrum of unrelated physical or psychological qualifiers, a suggestion that is more in the spirit of meaning acquisition seeking a high degree of internal validity would consist of *adapting indirect measures all along*.

Regarding questionnaire development, the dilemma of using a direct versus an indirect approach for inquiring about pain and related-suffering involves integrating the term “suffering” into the questionnaire instructions or in the evaluation tool versus no mention of the targeted notion whatsoever. Identifying the level and nature of suffering may either consist in directly asking the responder to rate their suffering experience (“Please indicate to what extent you may be *suffering* if”, for example, “the pain makes you feelangry/helpless/annoyed”) or else collect the information on suffering in an implicit manner through a set of attributes coming together to reflect the subjective experience (“Do you have the impression that”, for example, “the pain makes you feel angry/helpless/annoyed?”). Alternatively, the focus could also shift to introducing the term “suffering” in the measurement tool of the scale as we have done in our psychophysical studies (Bustan et al. 2015). Using a direct approach, we asked the participants to rate the Intensity, Unpleasantness and Suffering in response to the noxious stimuli using, for example, endpoints on visual analog scales (VAS) ranging from no pain, unpleasantness or suffering to extreme pain, unpleasantness or suffering. To ensure participants based the pain evaluation on their own pain and related-suffering concepts and representations, no previous definitions were given for the respective parameters.

Those who may, however, disagree with this direct approach warn against the use of a suffering scale to denote what we wish to assess, arguing that such explicit articulation might in itself affect the reliability of the answers. Instead, the picture of suffering is supposed to emerge from the sense provided by the items (expressions) chosen by the participants, unraveled by the various qualifiers that form a comprehensive perspective of this investigated phenomenon. And indeed, in the majority of cases, questions about pain states in the numerous evaluation instruments adapt the indirect approach as, for example, in The Pain Catastrophizing Scale (Sullivan et al. 1995), the role of perceived injustice in the experience of chronic pain questionnaire (Sullivan et al. 2008), and the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983).

This standard indirect approach, not only to questionnaire development, cannot however prevent us from wondering: “Can we obtain a more accurate picture of pain-suffering by compelling the individual attention to look at it directly?” This view supposes that knowing one’s pain is intrinsic to the pain experience and could serve its understanding by others. It also insists on avoiding usurping the patient’s authority to judge their suffering. Exceptionally, if a person is alexithymic and is thus unaware of his inner feelings [a trait comorbid with enhanced pain (Baudic et al. 2016)], detecting his suffering based on questions requiring him to distinguish and appreciate emotions and cognitions may be challenging. But in the majority of cases, introspection on pain and suffering assures exposure to their specific *mode of being* in a person. The return to self creates a proximity that allows for a literal expression without approximation. It opens the way for a clear articulation of suffering without having to derive it from *referring senses* in sentences that neither pronounce nor intentionally designate it. In addition, unlike the descriptors collected implicitly, direct enquiries do not require to make a detour by computing suffering as supervening on the various pain manifestations and no distance must be kept for evaluating the situation in an impersonal and supposedly more objective way.

Clearly, the suspicion regarding directly collected testimonies weighs not only on the intentions behind these reports, as mentioned earlier with the battlefield example, but also on their impossibility to exhaust all possible aspects, especially those that the individual may not admit to himself. Yet, what is at stake in this process of evaluation is not only epistemological, confronting scientific and philosophical stances on the question of how to best know these human conditions, nor is it simply methodological, seeking the most viable and effective approach to engage in the inquiry of deciphering the pain experience. The true difficulty with evaluating human pain and suffering in clinical circumstances concerns the need to expose how these phenomena appear in subjectivity without further hurting the sensitive individual when trying to recover maximal information. The view of suffering in pain is illuminating, but the possibility of penetrating this experience depends on whether a person has or has not integrated their chronicity, amputation or illness as part of their lived reality so the exposure to its meanings and consequences can be addressed. Admitting that the pain is part of me, of the person I have become, allows the digging into the open wound in search for personal senses of the agony and despair the subject would otherwise tend to dissimulate. Self-consciousness requires assuming one's own condition and coming to terms with the fact that pain is part of a daily reality. It allows describing a relationship with what inevitably coincides and is inseparable from my impoverished self. In this respect, a standardized approach looking for one objective tool to assess every patient on an equal basis might not be advisable as a normative rule. This thus raises the third possibility of using a direct (deliberative) analysis of pain-related suffering meanings for those who have fully integrated their illness but adopt a more indirect (evocative) form of evaluation for those who have not yet fully assumed their condition and who are therefore unable to report about what remains *ungraspable* for them. This point is stressed throughout Wittgenstein's argument that knowing I am having pain does not mean I know the pain, to which I would add: and that I could actually interpret it for explanatory purposes.

5 Two Types of Meanings for Deciphering Pain and Suffering

The third and last issue challenging the study of meanings of pain and suffering concerns the assumption that these phenomena should be thought of as underlined by two very different types of meanings. Together they illuminate the individual experience, thus requiring investigations to unravel both aspects. With respect to the aforementioned paradox of pain, the major contribution of the enquiry about both meaning types consists in filling the gap created by the invisible and thus imperceptible character of pain, making sense of an experience announced by an obvious physical event that may be missing a perceptible substance. Thus, despite the great confusion caused by the possibility of lacking a pictorial representation of pain (unlike the visible tumor), studying its meaning can provide a conceptual equivalence, a content matter, for transcribing both the felt sensation and the accompanying negative emotional-cognitive load. This process involves two types of meanings unfolded in the expression of pain and related-suffering:

The first and more *objective* type of 'meaning as elucidation', evokes the qualities of pain as symptom descriptors thus answering the requirement to provide a matter-of-fact knowledge that may be objectively evaluated. It can be acquired by identifying the specific qualities of the pain (continuous, intermittent, burning, sharp, cramping, surface vs. deep pain etc.) and the individual concept of suffering (for example, quoting a patient: "Suffering is to feel hurt, it hurts you, incapacitates your body and keeps you from living normally, and even if you have other things going for you, you cannot"). This first type transcribes the nature and reality of the phenomena according to the particular way a person expresses them (their mode of presentation). Typically, they are collected, albeit for the suffering aspect, by generic pain questionnaires such as the McGill Pain Questionnaire (MPQ) (Melzack 1975, 1983), the Neuropathic Pain Scale (NPS) (Galer and Jensen 1997) and the Multidimensional Pain Scaling (Clark et al. 1989).

The second and more *personal* form of 'implied meaning' reflects the internal value a person ascribes to his lived pain (annihilating, threatening, diminishing) and suffering (for example, quoting the same patient: "I suffer because of my health problems. This is not a mental suffering, rather physical suffering because it prevents me from carrying out my plans"). The latter meaning type cannot be substituted for the former as they are essentially different. If rigorously investigated, the notion of 'implied meaning' does not simply add another variable to the already complex elucidation of these phenomena. Rather, by expanding the examination of pain against the typology of symptoms and behaviors to include *subtle nuances* and *personal implications*, we may obtain precise information that is more compatible with the individual mode of experiencing pain and related-suffering. Thus, we are not simply speaking here of interpreting the aversive character of pain for unraveling its objective identity (meaning as elucidation), but of discovering the implied meaning it carries for oneself in life according to personal aspirations, conceptions and values. This may be accounted for when dealing with *what matters most for oneself* in the pain experience, exposing its singularity for the individual. For example, for a 50 years old patient I interviewed with neuropathic chronic pain eliciting permanent sensations of burning in her hands and a loss of equilibrium, it was—surprisingly enough considering the permanent burning pain—rather her declined sense of femininity that was repeatedly reported as determinant:

> I walk like someone who has been drinking. As if I have boots full of mud, like a cosmonaut. Even now. I lost my femininity because I cannot put high heels. Even with earrings, I drop them every time. Putting makeup lasts for hours. When I touch wool, it burns, as if I have no flesh on the skin. When I try to remove the Tampax, it is sometimes impossible. It burns me constantly, I do not feel my hands or the things that I touch. With my feet it is the same. I want to jump from a building. It lasts for 3 years now.

She adds, replying to my questions whether she considers herself as a person who suffers and what type of suffering is associated with her experience:

> I just told you, I am suffering. Emotionally, I lost my femininity, it is so bad one feels like crying all the time. But who can stand this physically, it is like I have two irons, I cannot stand straight and I have to force myself to do everything. I struggle. You see. I want to sleep because I cannot stand. Mentally, one suffers so much, everything is distorted by the disease. Here I am in front of you, I feel like in a fog and I feel that everything is wrong, I'm not here. As if I'm not here. I'm exhausted, I do not know what to do with my hands and instead of saying hell to everyone, I smile even though I am suffering. […] I fight against an evil, evil.

Thus, the first elucidation phase targets the objective qualifiers (burning, imbalance) and the way pain or suffering exhibit themselves for a more refined diagnosis of the condition. The second phase of implied meanings can teach us what really bothers the patient, thus providing relief by recognizing the obsessing burden (loss of femininity) and then working on reducing its impact by giving a new and more rewarding meaning. While working with chronic pain patients, I have noticed how important it is to look into both meaning forms. The first form can be said to be more 'rigid', often retaining the same significance across time while the second form varies from occasion to occasion according to the evolution of the illness and the personal situation. Thus, even if the incapacitating sense of burning pain (meaning 1) can be a dominant attribute for neuropathic chronic pain, it can be accounted for as either diminishing (meaning 2), annihilating (meaning 2) or rather manageable (meaning 2), depending on the patient and his condition.

Yet, the problem is that there are a few attempts to compute or categorize these meanings in the literature, either resulting in associating them with the first form of meaning as elucidation or, more rarely with the second, but not with both and not in a distinctive way. The only exception is Eric Cassell who raised the idea of using meaning to better understand patients over thirty years ago (Cassell 1991). Unjustly denoting the "sloppy" work of philosophers and in particular philosophers of language who define the term meaning in 16 different ways (philosophy like science evolves and moves forward to integrate new perspectives), he than selectively assigns meanings to the two categories of significance ("what something is") and importance ("contains the value element of meaning") (1991, p. 232). There is, however, no indication in his writings of how to apply this distinction *consistently*:

> "Another aspect essential to an understanding of the suffering of sick persons is the relation of meaning to the way illness is experienced. The word 'meaning'", Cassell explains in a summary article, "is used here in two senses. In the first, to mean is to signify, to imply. Pain in the chest may imply heart disease. We also say that we know what something means when we know how important it is. The importance of things is always personal and individual, even though meaning in this sense may be shared by others or by society as a whole. What something signifies and how important it is relative to the whole array of a person's concerns contribute to its personal meaning. 'Belief' is another word for that

> aspect of meaning concerned with implications, and “value” concerns the degree of importance to a particular person” (Cassell 1982).

Cassell’s inspiring insight of meaning as importance is similar to the earlier discussed second and personal form of “implied meaning”. But his claim that the basic meaning form is understood as a reference, a sign referring to an illness or an expression assigning a content matter naming pain (“it hurts”) seems however too narrow. It treats meaning as an object, assembling a standardized set that constitutes a sort of *inventory* of the pain properties, symptoms and correlated states. This indeed assures, as the physician points out, better identifiers for predicting the disease and providing a morexis (1991, p. 264), especially for pain patients who go through a myriad of physicians and unnecessary medical interventions, often hearing that they do not have a real disease, until a pain specialist finally recognizes their pathology.

At the same time, this first definition of Cassell closes the canon on the advantages of meaning as use, dismissing the possibility that the meaning of the pain complaint is not fixed, or prescribed, or predicative, but rather remains influenced by a sway of changing contextual factors, the way we employ words in the individual lifeworld. Interestingly, Cassell indeed admits to this point: “The kind of meaning that is the basis of this chapter is less stable, it may change from moment to moment as events, circumstances, utterances” (1991, p. 232). But the pattern he eventually adopts for interpreting the discourse of the patient relies on an ontological rule (“what is x”). I tend to think that this misconception comes from the tendency of the medical world to think of itself as universal, adopting a globally standardized approach applicable to all, even with meanings. Yet, we cannot describe pain meanings based on an open and formal system governed by the investigation of the invariants across conceptual changes (the definable thing depicting pain), when what we also seek to expose is the ongoing, situational and personal sense of the pain experience.

To recapitulate this third and last issue: pain meanings can be distinguished if we look attentively enough and acknowledge that there is something more than the scientific list of signs to account for, that they are dynamic and not fixed entities. The consideration of “meaning as use” shows that meanings are not just a list of properties implying what something refers to, but also reflect different aspects for different people with the same pain conditions but with very distinct sets of values. Overall, since the point is to acquire a better conceptual equivalence of the private world of the pained and to include personal meanings that shed a light on the particular way pain plays a role in one’s story, we need to go beyond the set of nociceptive and affective features coming together in a specific but quite mechanistic configuration in the various classifications procedures. This is better studied with the second meaning form, seen against a system of beliefs and concepts as well as in reference to the actual attendance of the subject to the direct experience (Williamson et al. 2015).

6 A Tool for Elucidating Pain and Suffering

The challenge is therefore to find the best paradigm for naturally yielding both meaning types. This is claimed to appear in the experiential-phenomenological approach of Price and Aydede (2005, p. 243–273), and although constituting a good basis for work this approach was not operationalized for clinical use. As a theoretical and practical tool for deciphering pain and suffering meanings, it must answer the needs of a large population of patients. It must be attentive to language, context, associated concepts and beliefs as well as the different pain conditions of patients in order to allow for the individual characterisation of pain and suffering. The merging of philosophy with science and medicine here is therefore essential as it seeks to highlight suffering and pain *as a lived event* including their multiple facets (e.g., situation, emotional state and cognition). Focusing on *circumstantial and contextual manifestations* will help to explain variations in a patient's distressed reaction to a repeated illness, why individuals differ in their responses to an identical malady, or why similar traumatic events play different roles in the experience of social groups.

In *clinical settings*, patients commonly rate their pain employing numerical ratings or visual analogue scales that classify pain on a scale ranging from "no pain" to "worst pain imaginable". Such ratings are often accompanied by a request to describe what they sense using adjectives as "dull", accompanied by the request to describe what they sense in using adjectives such as "dull", "sharp", "crushing", "fearful" or "excruciating", allowing the physician to assess the level and the type of pain (e.g., McGill Pain Questionnaire, Melzack 1975). These scales, along with other pain assessment tools that also evaluate the impact of pain (e.g., West Haven-Yale Multidimensional Pain Inventory; Kerns et al. 1985), help to communicate and quantify the subjective experience of pain. However, these scales do not convey the patients' full emotional state and, especially, the suffering resulting from the turmoil a person is undergoing. Although it is common practice, patients are not always able to relate to these key measurements (especially with the numerical scales of 1–10), considering it reductionist and inadequate for describing their experience (Williams 1996; Wlliams et al. 2000).

Our attempts in the *laboratory* with healthy volunteers to identify physiological and objective markers for acute pain and its related-suffering by measuring transpiration, heart rate, respiration and facial muscle activity explained some of the variability of suffering. But when combined with the pain-suffering ratings and qualitative data from questionnaires as well as interviews, a substantial increment in understanding the suffering component was achieved (Bustan et al. under review). What we come to learn is that psychophysics, measuring the sensations that are associated to physical changes, gives us the possibility to quantify our perception, but it does not expose the meaning attached to the subjective experience. This brings us back to the initial view expressed, calling for a combination of approaches for elucidating pain and related-suffering.

Another challenge for the development of a meaning acquisition tool consists of overcoming the frequent confounding between pain and suffering (Ricoeur 1994).

In shedding light on the nature of all three pain dimensions (intensity, unpleasantness and suffering), important information can be gathered on their extent and nature as well as their utterances. I also tend to believe that a systematic collection of both meaning types may avoid the frequent mix between pain and suffering in clinical practice, as noted by Fordyce (1988), and recently demonstrated in a statistical review by Fishbain et al. (2015), who examined 740 references addressing the expression of suffering in various patients' cohorts (chronic pain, advanced and terminal cancer, hospice group).

The matter is important because it may allow us to tackle two critical—but frequently overlooked—difficulties faced by medical staff today: first, patients' overrating pain and second, the negative correlation between reported pain and suffering states. Regarding the first, I assume that difficulties in clinical pain assessment such as frequently observed extremely high pain ratings could be related to not explicitly documented levels of suffering that often remain confounded with pain intensity and unpleasantness. In reality, it is unlikely that values of 8 or 9 out of 10 for people who endure pain over months and years reflects only chronic pain intensity. In analysing the different senses attributed to the individual experience, the "suffering" component of chronic pain can be assessed independently in the clinical setting. This characterization may have an impact on patient management, especially regarding a second common clinical finding of two emblematic categories following treatment: those who continue to suffer despite a significant reduction in the intensity of the pain, and those in whom the intensity of the pain remains high but who report no suffering. In better differentiating pain and suffering in chronic patients experiencing their conditions as a way of life by learning the specific meaning attributed to each aspect, we not only untangle the confusion between pain and suffering, but also categorize their nature.

In closing, while the focus of the current chapter was to present the importance of meaning acquisition for better understanding and assessing the lived experience of pain and suffering, there is clearly a need for accumulating empirical evidence in order to establish it in the scientific discourse. Recent findings in our laboratory show (Bustan et al. under review) that the three dimensions of pain-related suffering (physical, emotional, mental-cognitive) are all expressed by healthy humans in conditions of acute pain in a way that depicts the characteristics of suffering as an episodic *feeling*. However, existential suffering over the life span requires a sustained *condition* that can only be observed in mental and physical chronic illnesses in the clinical setting. Due to the dual nature of suffering (a feeling and a condition), the lack of one universal essence or ultimate element that an individual can easily identify from its manifestation plays an important role in the puzzles these phenomena raise today in philosophy and in the science of consciousness. Although in admitting to continuous variations in meanings a person attributes to personal pain, a rigorous operationalized conceptualization of the pain-suffering mosaic could create a strong basis for future investigations, possibly contributing a major step towards personalized therapy.

Acknowledgments I wish to thank Herta Flor, Caroline Casey, Nir Shalev and Simon van Rysewyk for comments and revisions, as well as to Didier Bouhassira, Nadine Attal and Jean-Marc Benhaiem for stimulating discussions and remarks.

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