

# Understanding pain and human suffering

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## Abstract

In the twentieth century the knowledge regarding pain, especially at the neurophysiological level, and in particular neuropathic pain, has increased. But more knowledge and analgesic medication devalued the doctor-patient relationship, sometimes ignoring the complexity of human suffering, far beyond pain. This is associated with a huge investment in biochemical research at the expense of training health professionals, especially doctors, in communication and caring skills. Several researchers have highlighted the need to (re) evaluate suffering in the formal and informal training of caregivers. The main purpose of this article is to recognize the potential that suffering can bring to the development of personal identity, stressing the role of communities in understanding these human experiences.

**Keywords:** Pain. Stress. Training. Caregivers.

## Resumo

### Para compreender o sofrimento humano

Durante o século XX, aumentou o conhecimento sobre dores, sobretudo em nível neurofisiológico, nomeadamente dores neuropáticas. Essa ampliação do saber e a proliferação de medicação analgésica – associadas ao enorme investimento na pesquisa bioquímica em detrimento da formação de qualidades comunicativas e cuidadoras dos profissionais de saúde, em especial dos médicos – desvalorizaram, porém, a relação médico-doente, ignorando por vezes a complexidade do sofrimento humano para muito além da dor. Vários investigadores têm sublinhado a necessidade de se (re) valorizar o sofrimento na educação de cuidadores de saúde, do nível formal ao informal. Reconhecer as potencialidades que o sofrimento pode trazer ao aprofundamento da identidade pessoal, salientando o papel das comunidades para a compreensão dessas experiências humanas, são os principais propósitos deste artigo.

**Palavras-chave:** Dor. Estresse fisiológico-Estresse psicológico. Cuidadores.

## Resumen

### Para comprender el sufrimiento humano

En el siglo XX, se incrementó el conocimiento del dolor, especialmente a nivel neurofisiológico, como en relación con el dolor neuropático. Más conocimiento y medicamentos para el dolor devaluaron, sin embargo, la relación médico-paciente, ignorando a veces la complejidad del sufrimiento humano, mucho más allá (y mucho más frente a) el dolor. Tal relación se asocia con una gran inversión en la investigación bioquímica a expensas de la formación de cualidades comunicativas y cuidadoras de los profesionales de la salud, especialmente los médicos. Varios investigadores han puesto de relieve la necesidad de (re) valorar el sufrimiento en la educación de los cuidadores de salud, al nivel formal e informal. Reconocer las potencialidades que el sufrimiento puede lograr en la profundización de la identidad personal, haciendo hincapié en el papel de las comunidades en la comprensión de estas experiencias humanas, son los principales propósitos de este artículo.

Palabras clave: Dolor. Estrés fisiológico-Estrés psicológico. Cuidadores.

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Declara não haver conflito de interesse.

It is usual to identify pain with suffering, even though, in strict terms, these are different realities. While pain always has a physiologically detectable support, in suffering, it is often not like that. Saunders<sup>1</sup> (in the 1960s) proposed the concept of “total pain”, but contemporary conceptions of suffering are even more complete than those of the founder of the *Hospice* movement. This is due mainly to the technological innovations that allowed for a better understanding, for example, of the physiological mechanisms that produce pain. This research was performed to 1) reflect on the possibility of there existing ontic discontinuity between pain and suffering, 2) contribute to a better understanding of these human experiences, and 3) better base the training of more insightful and compassionate health care workers.

### On pain

The most common definition of pain in clinical practice identifies it, more or less consciously, as a signal provided by altered bodily tissues. Pain always occurs as a manifestation of physiological alterations with cause that auxiliary diagnostic techniques usually identify. Most times when this does not occur, people who complain of pain are told that it does not result from a condition in their bodies, but from “psychological factors”<sup>2</sup>.

This apparent diagnosis manifests another belief widespread among health professionals: what is on the psychological level does not exist, it is imaginary, it is *only* mental, that is, the mind is not part of the physiological order, does not live immersed in a body. The assumption made here is the division between mind and body; this belief (frequently not conscious) depreciates situations in which there is pain without a detectable dysfunction, like in the case of phantom pains, pang, etc. given the impossibility of evaluation as visceral or somatic pains, these are sometimes declared by health professionals as mental or psychological, being thus depreciated for (in this line of thought) not being physiologically justified. Facing this type of diagnosis, users usually make the same interpretation. Many do not make additional appointments; others are sent to psychiatrists, where they are frequently assessed only at the brain level<sup>3</sup>, although the neurological function encompasses the whole human body<sup>4-5</sup>.

### Definition

Attentive to the problems caused by this type of belief about pain, the International Association

for the Study of Pain (Iasp) defined pain, almost 20 years ago as *an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*<sup>6</sup>. It is assumed that pain has a deeply subjective dimension, for being an experience.

The dominant paradigm in formal health care is biomedical, one of its features being the production of descriptive and objectifiable knowledge. This definition continues to link pain only to its dysfunctional dimension, not considering the existence non-physiological pain as a hypothesis, *tout court*. This existence is admitted only as long as science does not have the instruments/knowledge to find the linear cause for all types of pain. It is peculiar that the argument for this rationale is linked to the Aristotelian language (*potential* or *actual*). However, the inclusion of the emotional dimension in the definition of pain by the Iasp represents change, allowing this aspect, of a markedly subjective nature, to be associated to the present (and traditional) physiological dimension of pain.

When it is not possible to identify the cause for a complaint of pain, it will be more sensible to admit one’s ignorance than to implicitly classify this perception as unreal, labeling it as “psychological” or “somatic”. The medical class sometimes imposes to patients its representations and meanings on suffering in such a way that these end up opting for the solutions that derive from these assumptions, to which they are pressured. *It is an imaginary of techno-scientific origin that determines the present perception of pain and suffering and explains many of our behaviors, as in the case of those women who, from genetic tests for cancer. Opt for the most radical solution, ultimately not escaping new ways of suffering*<sup>7</sup>.

Whatever the causes of pain, they take place in a body in which the nervous system has a very important role. A European study on chronic pain<sup>8</sup> performed with about 46 thousand people from ten countries found that one in every five adults suffers from chronic pains, lasting for seven years on average, sometimes lasting for twenty years or more. In another study<sup>1</sup>, 40% of the chronic patients point to the impact of pain in their daily lives. Many of these patients were not evaluated or diagnosed, nor were their pains adequately monitored.

### Scales of pain

There are some scales to classify pain, although it is recognized that none is totally reliable.

The analogical ones are used with children and adults who do not express themselves verbally. The ones of visual analogical type show a 100mm line in a ruler, representing the intensity of the pain felt in numbers from 0 to 10. They are used mainly for the prescription of medicines but they may also be a fundamental resource for diagnosis, for example, in physical therapy.

Another instrument to classify pain – the most complete in our understanding – is the McGill-Melzack questionnaire, which is very appreciated for trying to assess pain both in quality and in intensity. Categories are distributed in several items, making possible a quite varied range of choice by the patient: some refer to sensory symptoms, some to the affective dimension and others to some particular aspects. The language employed refers to the vocabulary normally used by patients instead of being linked to the technical nomenclature<sup>9</sup>.

### Classification

Pain can be considered acute or chronic (concerning intensity); the first is an alert from the organism in face of mechanical, chemical or thermal; the second causes organic imbalances, progressively decreasing the functional capabilities of people. The most common physiological typology includes somatic, visceral and neuropathic pain. In the first, we have pains resulting from damages which are “external” to the body, while visceral pain refers to pains which are internal to the organs (the classic symptoms are abdominal cramps). Both are in the nociceptive order: the sensory experience that occurs when specific sensory peripheral neurons (nociceptors) respond to harmful, usually acute, stimuli. In turn, neuropathic pain results from dysfunction in the nervous system itself. These mechanisms only began to be understood at the end of the last century<sup>10</sup>. Often, in chronic situations, pain is not located in the region of the lesion, but in the nervous structure affected (nerves, nerve cord, brain, for example), thus, not decreasing with usual analgesics.

If the McGill-Melzack scale classifies pain as sensory, affective and evaluative, Saunders makes a distinction between *pain* and *total pain*. The former refers to the physiological dimension, the latter to the psychological, social and spiritual domains associated to the former<sup>11</sup>. This author found that a great deal of the suffering of cancer patients resulted from the connection between the acute pain of the physiological type and relational questions of the patients with themselves and with others

(especially the family and entities considered to be transcendent).

Much of what torments these people refers to guilt, frustration and powerlessness related to situations they lived in the past or would like to live in the future. Making sure that their beloved ones are well and have means to keep living well in the future is another great concern, as well as the possible purpose or meaning to their pain, or their right (or not) to eternity. This theme can be addressed in details by the study of the stages described by Kübler-Ross<sup>12</sup>, among other later authors.

The definition by Saunders was innovative for its time and it was also very important because it opened the way to palliative care. However, this view still has epistemological roots in the dualist perspective of the mechanistic paradigm to which the biomedical perspective belongs. Indeed, the physiological dimension is not only inseparable from the other types of pain but it also assumes, paradoxically, that the whole (the *total pain*) equals the sum of the parts (several types of pain), which is the fundamental hypothesis of modern mechanism<sup>13</sup>.

Pain scales consist in attempts to measure a subjective experience and, when they are not handled by the users but by health professionals (usually nurses), their credibility decreases enormously. Their quantifying aspect also allowed for the development of analgesic protocols for each number *item* on the scales, which are often ineffective in autoimmune diseases because the type of pain associated with them does not decrease with the medication filed to the level and intensity reported by users<sup>14</sup>. Most of the pain associated to these conditions (fibromyalgia, lupus, etc.) is of the neuropathic type and there may be different intensities of pain in different parts of the body at the moment when the pain is assessed using the scale, for example.

Thus, as the understanding of neuropathic pain grows, the sensitivity of professional caregivers to the subjectivity inherent to any type of pain should also increase. Knowing how to listen and getting to know the user well, through their narratives, produces better knowledge about an individual's pain than any other way of measuring pain<sup>15</sup>.

### On suffering

Different cultures have different conceptions of suffering. For example, the Buddhist culture faces suffering as integrated to the everyday life of people. In our culture, different types of understanding about suffering and the way to feel it came up with

time. Even in an approach limited to a precise historical moment, such as the present, we may find more than one connotation; for example, as mentioned, it is usually associated to pain.

### Definition

Facing the multiple definitions, an option was made for the classical definition of suffering in the world of health, as described Cassell<sup>16</sup>, as it allows for the clarification of some experiences of suffering not always evaluated as such. Thus, generically, suffering is *a state of severe distress associated with events that threaten the intactness of the person. Suffering requires consciousness of the self, involves emotions, has effects on the person's social relationships, and has an impact on the body*<sup>16</sup>. This existential situation of severe distress is found in what the person identifies with his/her interior, usually associated to emotions, like anxiety, and feelings, like sadness, frustration, powerlessness, etc. The fact that it is part of an inner experience makes it not always detectable by an observer.

Suffering always arises associated to events, especially external events (other people, disease, unemployment, loss of a loved one, etc.). It is important to highlight, however, that the state of severe distress is felt inside; thus the usual hypothesis of damage to some internal organ like the heart, liver, etc. When this happens, even if auxiliary diagnostic exams do not point to anything, health professionals must be very careful before concluding that there is nothing there that concerns them. Even if the cause of suffering may be considered external, it cannot be mistaken with the effect produced (suffering), or reduced to that only cause.

### Holistic dimension of suffering

Much of the patient's suffering is related to other factors beyond their physiological problems. Someone diagnosed with a disease feels fragile, or believes he/she should feel that way; and believes to have physiological limitations usually described by health professionals. This situation affects the way one eats, moves and interacts with oneself and with others. Less positive moods are frequently manifested in ill people and, in what refers to people with chronic diseases, the possibility of reaching depressive states is not small. It is common for them to feel not sufficiently supported, not taken seriously, etc.

The patient also has concerns of a collective nature that may cause great distress, given that his/her absence (be it temporary or definitive) may result

in difficulties for the family, the company where the patient works, to the friends that support him/her, etc. The problems experienced (or postulated) by the patient are connected to the social roles he/she has, not only to the disease. As an example, the patient may be the emotional support for someone – such as a child, partner, friend, parent or grandparent – or that the household expenses may depend on the wages of the patient unable to work.

Being ill may also impose questions on the meaning of life and death, on what we are doing here, as well as on what we ought to do; are we in transit to another dimension or is this the last stage of others before us? Philosophical concerns that assail any human being in moments when the end happens to be glimpsed<sup>17-21</sup>, as Tolstoy reminds us: *But what am I here to harangue: What is the purpose of existence? It can't be that life is so senseless and horrible. But if it really has been so horrible and senseless, why must I die and die in agony?*<sup>22</sup>

All this is part of the severe distress a diseased patient goes through, but with the aggravation, that all these issues exist and are not categorically organized, vibrating with noise within the person. This multiplicity of aspirations, sadness, pains, frustrations usually creates a feeling of discouragement, a sensation of total helplessness in the face of life and of what gives it meaning: those who they love reciprocally. The sensation of internal disintegration is real and often accompanied by visceral sensations. People often describe this saying that they are “swallowing themselves” or use similar metaphors. This “un-identity” is physically manifested also by the sudden and severe loss of weight, because suffering at times corresponds to giving up the fight, the abandonment of this person – who no longer recognizes him/herself as “self”<sup>23</sup> – to his/her fate: *As if I had just started a process of depersonalization. I had transferred myself to a subject in the third person*<sup>24</sup>.

Many times, however, suffering takes place without any physiological disease. Some factors socially attributed to suffering are mourning for the ones we love, powerlessness, abandonment, torture (emotional, for example), unemployment, betrayal, isolation, lack of shelter, loss of memory and fear<sup>17-21</sup>. There are, however, many other situations, like being in love with someone who rejects us. Being a subjective experience, we can live in suffering situations that do not cause any other type of distress to other people: *who suffers my suffering is only me and no one else*<sup>25</sup>, we are reminded by António Gedeão. The subjective specificity of

human suffering is also found by the possibility of it occurring from any dimension, although it is the person as a whole who suffers.

### Person and suffering

When we state that it is a person who suffers and not a body (or organs, or cells in bodies) we do not identify a person with the person's mind. We live in a time fascinated with human mental abilities and their functions. The science of the very small dreams of discovering mechanisms to unravel the pathways and mental orders that, in the paradigm of contemporary science, are believed to be in the base of every human activity. But this is, once more, a modern mechanistic conception that makes us forget that the mind (whatever that is, for there is no consensus on the subject) works in a brain that inhabits a body.

There are, obviously (and as has always been), scientists that try to demonstrate that these beliefs may be changed, but these are the minority because, in the present days – as Feyerabend<sup>26</sup> reminds us – to be a scientist and to stand against the dominant paradigm requires as much courage as in the time of Galileo. Thus, some neuroscientists have shown that self-awareness, necessary for the experience of suffering (but not for that of pain), emerges from the holistic functioning of the human body<sup>27</sup>, in which the brain immersed in a continuous neural network<sup>28</sup>. Human suffering is produced in this network, affecting the whole being of the person affected, although it may focus more strongly in a certain dimension (emotional, physiological, spiritual, ethical-moral, etc.)<sup>29</sup>. Giving care to someone who is suffering implies interacting with all these dimensions, not only with the physiological dimension, as in the case of nociceptive pain.

### Suffering and time

Suffering has a peculiar connection with time. Thus, the anticipation of the experience of pain (facing a diagnosis of paramyloidosis, for example, in someone who has taken care of a relative who died due to this neurodegenerative condition) may cause suffering and seldom pain. It may anticipate suffering experiences: "if the pain I feel comes from a cancer, I will die". The fact that we can suffer for what we will, supposedly, live in the future can be used in the opposite direction, that is, we can decrease suffering using its close link to the personal dimension. So, for example, a terminal patient may reduce his/her present suffering by establishing small short term goals that are fulfilled or seen to

happen; for example, to ensure that the study of his/her younger children will be paid for with money kept with someone trusted for this purpose. *It is the notion of time that relates the images (...) and gives them the light and the tone that gives them date and makes them meaningful. (...) Because memory, I learned on my own, is indispensable for time to be not only measured but felt*<sup>30</sup>.

### Chronic diseases

Until the middle of the XX<sup>th</sup> century, the disease that killed the most in Europe was tuberculosis, but with the antibacterial success, its expansion could be controlled<sup>31,32</sup>. Since the 1950s, the frequency of neoplasias have been increased all over the world, with growing epidemiological incidence until our days. In Portugal, neoplasias are surpassed by coronary diseases – there, the success of the control of infectious diseases occurs as well as the resulting increase in the average longevity. There are also other causes for this situation, such as diet changes, the insertion of women into the world of remunerated labor, climate and demographic changes, etc.

Among the consequences of this change, we stress the need for greater (and longer) clinical contact with the patient: the number of patients that a physician (in the hospital context, for example) examines, medicates and never sees again is decreasing extraordinarily in Portugal. On the other hand, there are increasingly more people who feel they are almost part of the families of nurses and physicians by whom they have been treated for years.

### Physician-patient relationship

The training of formal health caregivers requires, thus, increasing attention regarding the physician-patient relationship, hence the movement around the world to (re)insert the study of humanities into medical education. In this sense, organs in the United States and Europe have determined that the principle of the well-being of the patient *is based on the dedication in serving the interest of the patient. Altruism contributes to the trust that is central to the physician-patient relationship. Market forces, societal pressures and administrative requirements must not compromise this principle*<sup>33</sup>. Another issue to which chronic disease leads is the the understanding that formal health caregivers must develop humility, which should be encouraged in their years of training.

Many chronic diseases are cataloged as being auto-immune, about which very little is known. For a broad range of these, what medicine can offer is palliative care, not treatment. Patient rehabilitation (albeit not total) is not sufficiently encouraged, contrary to other chronic diseases whose mechanisms are better known, biologically speaking (diabetes, coronary diseases, etc.).

Medical training, however, lies on the curative dimension or – when the cure is not possible – in keeping the organisms alive at all costs. These situations occurred until then, especially in what concerns terminal patients, but chronic diseases changed this situation. In this context, the function of physicians will be mainly to care for people who live almost identical daily lives as the ones who are not ill, since many of them work, perform family functions use their idle time, etc. – they are not acutely ill, they have a chronic disease<sup>2</sup>.

### Training

As referred before, medical training doesn't usually focus on the training of relevant competencies for the clinical practice with chronic patients, as it is founded on beliefs that make such investment impossible. Some of these, of the epistemological realm, will be addressed. As we know, medicine was, until very late, an art linked to the scholastic knowledge proper to European, mainly Mediterranean, universities. Hence its epistemological statute of applied science<sup>34</sup>. Le Breton calls it *the science of the diseased body*<sup>9</sup>, which refers directly to its deeply pathogenic view of the human being, explained and understood in terms of the mechanistic paradigm of modern physics.

Medical training lies on the belief in linear causality, or formal/efficient causality in Aristotelian terms<sup>2</sup>. As seen previously, it is still believed that the cause of a sign, or a symptom, always resides in a dysfunction in physiological terms, in the macro- or micro-scale, as minute as they may be. Hence, patients are subjected to continuous examination, of increasing precision, with the usually unshakable certainty that this unique, physiological cause will be found<sup>35</sup>.

In several types of chronic diseases, however, no structural changes are found in the suspect organs, but in the way these organs perform their expected organic function. The ones of the auto-immune type very frequently present such diverse symptoms that it is impossible to assume a single

organic cause. Either this single origin is considered as existing in the imagination of the patient (or in the mental realm, as we identify them) or it is assumed that there must be a variety of causes for the typological multiplicity of the malaise. This type of disease refers, still, to the possibility of circular causality and, if this is not understood, the cause may be taken for the effect and vice versa.

Physicians (whose training lies on laboratory and scientific investigation) rarely assume that they are observers in the performance of their profession. This difficulty exists because this training usually lies on the belief that the knowledge produced corresponds to the reality (theory of correspondence with the real, in epistemological terms), even if the patient does not identify with it<sup>35</sup>. Health professionals are trained who believe they act free from beliefs or psycho-social-spiritual representations, believing that what their bodies were subjected to in their existence does not influence the way of caring for others.

The highest possible emotional self-control is defended and, preferably, the nonexistence of emotions in the face of human suffering. We know this is impossible; the observer represents results (assessed by the observer) of his/her interaction with others and, fortunately, this is already assumed in some manuals of support to informal caregivers, and even formal ones<sup>36</sup>: *Through recurrent interactions with its own linguistic states, a system may remain always in a situation to interact with the representations (...) of its interactions. Such system is an observer*<sup>37</sup>.

Thus, the medical category faces a contradictory situation in relation to chronic disease. If, on the one hand, at the level of scientific investigation, biochemistry has invested a lot in this kind of disease, in what refers to the care of chronic patients, however, there is a long way to go in medical training and in the clinical practice. *It is necessary that we be educated facing our vulnerability and our feeling of vulnerability, it is necessary that education take this aspect as its responsibility*<sup>38</sup>.

### Care and community

Would it not be the responsibility of the communities in which these patients live to care for this malaise? Yes and no, because much of the suffering of chronic patients have origin in their community relationships. When diagnosed with this type of disease, the patient is usually touched by a wave of solidarity by relatives and friends. In the case of

“long term” diseases, however, this wave gradually fades; caregivers get tired of the complaints (which are also reduced with the decrease in the people who visit), get familiar with eating and motor disabilities, etc., and gradually forget they are dealing with people suffering great distress, the greatest of all being that they simply cannot be like the others. *While diseases, as they have been conceived of classically, are confined to the body and its parts, the illness of one person may be accompanied by disorder in that person's extended system - for example, associates, the family or even the community.*<sup>39</sup>

### Chronic suffering

In most diseases, suffering lasts for a shorter time than the treatment leading to the cure; one of the most important reasons for the relief of suffering derives from the analgesia provided by a first medical appointment. By contrast, chronic diseases entails increasing suffering as people will feel they are an increasingly heavy burden on the lives of their caregivers. Their identity is deeply linked to the lives of those they love reciprocally. Feeling they are hampering the lives of their loved ones, limiting the ones they love with the limitations caused by the disease, is something that becomes dramatic when the situation is turns out to be definitive.

These people usually experience suffering mixed with guilt and fear of being abandoned. Almost inevitably, they start to think the caregiver acts out of obligation and not for love. Overloading the ones who love them divides them in their own identity this situation leads to additional relational difficulties that reflect, for example, on the sex life of chronic patients, whether they have pains, motor difficulties, respiratory or vascular insufficiency, etc. In the case of women, suffering is easily accentuated given the complexity of factors involved in their sexuality,

### Social representations

In societies that value people with high emulation, who are admired by others, the ones who feel diminished by their suffering (physical, affective, spiritual, etc.) feel this suffering increase because they feel like failures for themselves, for others and even for transcendental entities in which they believe. Many people live in continuous double embarrassment<sup>40</sup>, oscillating between feeling they're treated unfairly and being unable to be like the others (or as they believe the others are, mainly due to

the images we are bombarded with by the media). For reasons like this, aging has become reason of suffering for almost all of us. It is becoming more and more difficult to perceive the existential wisdom that age brings, as we are focused on the lack of vitality, productivity, standardized beauty etc.

We cannot underestimate the impact of these social representations on people. Indeed, the desire to be recognized as normal, equal, is always present, even if not consciously. Admitting it, understanding it critically and perceiving the costs it implies must be parts of an education for suffering.

### Risk groups

There is, however, a type of persons who potentially live in chronic suffering: the “handicapped”. This refers to a type of suffering, usually without pain, but with an immense perception of interior disintegration, of loss of oneself. Many people in this typology could, and should, be usually called upon as sources of learning on suffering. Many other groups of people constitute “risk groups” in what concerns chronic suffering, namely those who represent the different, the strange, the disorder (people with physical deformities, scars, grimaces and uncontrollable tics, with mutilations etc.). It is found, however, that also obese people and people included in types of eating disorders, such as anorexia and bulimia, constitute risk groups, as well as people who never completed a salutogenic (although full of suffering) process of mourning, who live in pathological mourning.

### For an integrating view of pain and suffering in human life

Much of the suffering of the groups mentioned here is related to physiological or social dimensions, but some of this immense suffering springs from the people themselves, from the conflict of wanting to be who they are not and wanting to be accepted as they are, as human beings with the same rights and duties before others. Obviously this level of suffering arises from the physical and social conditions in which people live. One can, however, immensely decrease this suffering when one accepts the conditions in which one lives, trying to improve them not in function of others, but valuing one's specific situation. The importance of acceptance was addressed by Kübler-Ross<sup>12</sup>, among others.

The suffering of a sick person is very variable, even in ontogenetic terms, for the reasons

announced. The higher the intensity with which the pain is perceived, the higher is, in principle, the suffering perceived by the person. Hence chronic patients many times associate their suffering directly to the pain caused by the disease<sup>41</sup>. When asked in detail about this correlation, we find that much of the suffering is rather related to the lack of sense of internal coherence (SOC- *Sense of Coherence*) and failure in the creation/management of general resistance resources (GRR), placing people in processes of identity loss. Denial or anger at the disease do not provide suffering or the development of SOC/GRR<sup>42</sup>. This difficulty is often observed in caregivers<sup>43</sup>. The SOC refers to the ability any of us has to make sense of life, structuring us in the face of internal disturbances or the (perceived as) external ones. Not always are people who suffer the most able to (slowly) revert the situation into learning; this occurs with people who have already attributed (and constructed) sense in their daily lives, in other experiences prior to the suffering at issue.

However, in studies, we find other people who, in facing chronic disease, do not see their suffering being increased, as they integrate in their lives the pains associated to them. This is found in people who can attribute sense (or SOC) to their painful experiences<sup>44</sup>.

### Community dimension

In the theory of autopoiesis<sup>37</sup>, human beings are living systems of the third order, meaning that the community dimension is intrinsic to their biological identity. Constructing complex levels of autopoietic meaning presupposes, thus, the inclusion of those we love in this construction. With these people, we constitute one another around self-organizing patterns that make us give similar sense and value to suffering. For this, we help one another to find ways to resist suffering but also to accept it, relying on the resources the communities in which we live provide us<sup>45,46</sup>. *Autopoietic systems may interact with one another without losing their identities, while the different modalities of autopoiesis constitute sources of compensable disturbances*<sup>37</sup>.

Informal care giving belongs to the domain of communities to which one belongs. The social value of this dimension is under the risk of being lost, due to the highly competitive societies we live in, that link people almost exclusively to the labor world<sup>23</sup>. Giving care to someone who suffers requires patience, humility, compassion, detachment. When the suffering is associated to pain, it may also require professional care from health professionals, but informal care remains irreplaceable for the person's recovery<sup>46</sup>.

### Final considerations

Learning from suffering results from a slow easing of standards that must not lead to their rupture, under the risk of identity disaggregation. Hence the importance of training caregivers to assume the observational dimension, that is, the ability to deal with the mental representations about people they take care of as if these representations had ontological reality, as if they were the mirror of the one being taken care of. Keeping that in mind, caregivers will try to understand ways to punctuate reality turned into patterns of attribution of meaning in (to) the world of sufferers (using life histories and other types of narratives, for example). For such, they will have to establish relationships founded on empathy, humility and trust<sup>47,48</sup> that allow for structural couplings<sup>37</sup>, be it with the patients or with their informal caregivers.

It may happen that sick people with pain are not in suffering, in which case they have accepted their condition and have learned with it to strengthen the meaning of life. Only knowing them as human beings, and not only as patients, will we be able to identify if there is suffering or not and of what type it is. Informal caregivers are essential to this, and any health professional should have communication, anthropological and ethical training to learn to identify situations in which their patients need help in addition to medicines and more or less invasive treatments.<sup>49</sup> *It is impossible (not merely difficult, but impossible) to base solid clinical decisions solely on the scientific evidence because, as all science, the evidence is on generalities and patients are particular, unique individuals*<sup>50</sup>.

The almost complete domain over pain in the past century created the belief in many professionals (and even in the general public) that human suffering is also controlled. However, this has not happened, due also to the symbolic dimension that suffering has for each person, for each individual and even for a civilizational culture<sup>9</sup>. The creation of subjects in the humanities does not guarantee, by itself, a more comprehensive and humanizing training of health professionals<sup>51</sup>, because of several factors, such as the power of the mechanistic biomedical paradigm in the academia of the so-called civilized world.

Studies indicate that health professionals who had training in this area have underestimated it in such a way that, when in their clinical practice, they are unable to recall that much of the training they feel they lack was officially offered to them in the



academies. The ideal of the five star physician<sup>52</sup> is very far from being reached. and the epidemic of medical negligence in some countries shows it<sup>53</sup>. The professionals themselves are victims of a training that prepares them to be emotionless automata, leading them at times to exhaustion on all

levels<sup>54</sup>. Finally, it is necessary that informal caregivers, besides the formal ones, remember that there may be suffering without pain<sup>55-57</sup>. Living unstructured lives, devoid of identity and meaning is a danger not only for the people concerned, but also for communities<sup>23</sup>.

## Referências

1. Saunders C, Summers DH, Teller N, editores. Hospice: the living idea. Philadelphia: Saunders; 1981.
2. Munson P. Stricken: Voices from the hidden epidemic of chronic fatigue syndrome. New York: Haworth Press; 2000.
3. Coutinho JF, Fernandes SV, Soares JM, Maia L, Gonçalves OF, Sampaio A. Default mode network dissociation in depressive and anxiety states. *Brain Imaging Behav.* 2016;10(1):147-57.
4. Damásio A. The feeling of what happens: body and emotion in the making of consciousness. Nova York: Harcourt-Brace; 1999.
5. Varela FJ, Thompson E, Rosch E. The embodied mind. Cambridge: MIT; 1992.
6. Portugal. Ministério da Saúde. Programa Nacional de Controlo da Dor. Lisboa: Ministério da Saúde; 2008. p. 6.
7. Cantista M. A dor e o sofrimento. Porto: Campo das Letras; 2001. p. 217.
8. Fricker J. Pain in Europe: a 2003 report. [Internet]. Cambridge: Mundipharma; 2003 [acesso 27 jan 2015]. Disponível: <http://bit.ly/1UMyzW0>
9. Le Breton D. Compreender a dor. Lisboa: Estrela Polar; 1995.
10. Groopman J. The anatomy of hope. Nova York: Random House; 2004.
11. Pfizer. Programa educacional: compreender e diagnosticar a dor neuropática: dossier de formação. Lisboa: Pfizer; s/d.
12. Kübler-Ross E. Sobre a morte e o morrer. São Paulo: Martins Fontes; 1969.
13. Rorty R. Philosophy and the mirror of nature. Princeton: Princeton University Press; 1979.
14. Zelen M. Data analysis methods for inferring the natural history of chronic diseases. *Natl Cancer Inst Monogr.* 1971;34:275-82.
15. Tavares JF. Medicina narrativa: Alice no país dos provérbios. Lisboa: Euromédice; 2014.
16. Cassell EJ. The nature of suffering and the goals of medicine. Oxford: Oxford University Press; 2004.
17. Frankl V. Psicoterapia e sentido da vida. São Paulo: Quadrante; 1973.
18. Lukas E. Histórias que curam... porque dão sentido à vida. Campinas: Verus; 2005.
19. Fauré C. Vivre le deuil au jour le jour. Paris: Albin Michel; 2012.
20. Delecroix V, Forest P. Le deuil: entre le chagrin et le néant. Paris: Philo; 2015.
21. Neimeyer RA, Burke LA, Mackay MM, Stringer J. Grief therapy and the reconstruction of meaning: from principles to practice. *J Contemp Psychother.* 2010;40:73-83.
22. Tolstói L. A morte de Ivan Ilitch. Lisboa: Editora 34; 2006.
23. Le Breton D. Disparaître de soi. Paris: Métaillié; 2015.
24. Pires JC. De profundis, valsa lenta. Lisboa: Círculo de Leitores; 1998. p. 30.
25. Gedeão A. Obra completa. Lisboa: Relógio d'Água; 2004.
26. Feyerabend P. Science in a free society. Londres: New Left Books; 1978.
27. Damásio A. Sentimento de si: o corpo, a emoção e a neurobiologia da consciência. Lisboa: Europa-América; 2000.
28. Epstein R. Cognition, creativity, and behavior: selected essays. Westport: Praeger; 1996.
29. Cicurel R, Nicolelis M. O cérebro relativístico: como ele funciona e por que ele não pode ser simulado por uma máquina de Turing. São Paulo: Kios Press; 2015.
30. Pires JC. Op. cit. p. 31.
31. Mattson H, editor. Proceedings of the joint conference of the Finnish Anti-Tuberculosis Association (1907-1977) and the Europe Region of the International Union against Tuberculosis, Hanasaari, June 13-17, 1977. Copenhagen: Munksgaard; 1978.
32. Portugal. Direção-Geral da Saúde. Programa nacional de luta contra a Tuberculose: ponto da situação epidemiológica e de desempenho. [Internet]. 2013 [acesso 30 maio 2016]. Disponível: <http://bit.ly/1XTdL3N>
33. American College of Physicians. Medical professionalism in the new millenium: a physician charter. *Ann Intern Med.* 2002;136(3):243-6.
34. Caração J. O que é ciência. Coimbra: Quimera; 2001.
35. Groopman J. How doctors think. Nova York: Houghton Mifflin; 2007.
36. Jacobs B. The emotional survival guide for caregivers: looking after yourself and your family while helping an aging parent. Nova York: Guilford Press; 2006.

37. Maturana H, Varela F. De maquinas y seres vivos. Santiago: Editorial Universitaria; 1972. p. 90.
38. Vigarello G. Entretien avec Éliane Rothier Bautzer sur l'évolution des pratiques de santé. Les Sciences de l'Éducation: pour l'ère nouvelle. 2003;36(2):23-34.
39. Cassell E. Op. cit. p. 47.
40. Bateson G. Steps to an ecology of mind. Nova York: Ballantine Books; 1972.
41. Encarnação P, Oliveira CC, Martins T. Dor e sofrimento conceitos entrelaçados: perspectivas e desafios para os enfermeiros. Rev Cuidados Paliativos. 2015;2(2):22-31.
42. Encarnação P, Oliveira CC, Martins T. A generalized resistance resource: faith: a nursing view. Health Promot Int. 2015;1-4. DOI: 10.1093/heapro/dav114.
43. Oliveira CC, Costa AL. Viver o estado terminal de um familiar: leitura salutogénica de resultados de um estudo de caso. Saúde Soc. 2012;21(3):698-709.
44. Lindström B, Eriksson M. Contextualizing salutogenesis and Antonovsky in public health development. Health Promot Int. 2006;21(3):238-44.
45. Antonovsky A. The salutogenic model as a theory to guide health promotion. Health Promot Int. 1996;11(1):11-8.
46. MacIntyre A. Dependent rational animals: why human beings need the virtues. Londres: Duckworth; 1999.
47. Henry M. Incarnation: une philosophie de la chair. Paris: Seuil; 2000.
48. Machado J. Perspectiva antropológica do ensino da medicina. Acção Med. 2006;70(1):16-22.
49. Oliveira CC. Suffering and salutogenesis. Health Promot Int. 2015;30(2):222-7.
50. Maturana H, Varela F. Op. cit. p. 67-8.
51. Oliveira CC, Feio A. A formação académica em medicina. Acção Med. 2014;1:11-27.
52. World Health Organization. Developing protocols for change in medical education. Genebra: WHO; 1995.
53. Wachter RM, Shojania KG. Internal bleeding: the truth behind America's terrifying epidemic of medical mistakes. Nova York: Rugged Land; 2004.
54. Mata DA, Ramos MA, Bansal N, Khan R, Guille C, Angelantonio E *et al*. Prevalence of depression and depressive symptoms among resident physicians: a systematic review and meta-analysis. Jama. 2015;314(22):2373-83.
55. Oliveira CC, Pellanda N, Reis A, Boettcher D. Aprendizagem e sofrimento: narrativas. Santa Cruz do Sul: Udunisc; 2012.
56. Derrida J. Chaque fois unique: la fin du monde. Paris: Galilée; 2003.
57. Fernandes I. O elefante verde ou a importância da medicina narrativa na prática clínica. Rev Ordem Med. 2014;30(153):76-81.

