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UPDATE

Pain and suffering from the perspective of patient-centered care

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Abstract

This reflection aims to contribute to the application of patient-centered care in pain management in a hospital context. As a theoretical study, it seeks to stimulate discussion without exhausting arguments, considering issues such as the dimensions of suffering, pain neglect and its consequences, the relevance of the interprofessional approach, and the patient's human rights. An interprofessional team is essential for treating human pain and suffering, and care planning must consider emotional, economic and cultural aspects, providing physical and mental well-being. The interprofessional proposal goes hand in hand with patient-centered care.
Keywords: Bioethics. Delivery of health care. Pain management. Malpractice. Human rights.

Resumo

Dor e sofrimento na perspectiva do cuidado centrado no paciente

O objetivo desta reflexão é contribuir com a aplicação do cuidado centrado no paciente no manejo da dor em contexto hospitalar. Trata-se de estudo de natureza teórica que busca estimular a discussão sem esgotar os argumentos, considerando assuntos como as dimensões do sofrimento, a negligência da dor e suas consequências, a relevância da abordagem interprofissional e os direitos humanos do paciente. Conclui-se que é preciso haver equipe interprofissional para lidar com a dor e o sofrimento humano no contexto hospitalar, e que o planejamento da assistência deve considerar aspectos emocionais, econômicos e culturais, proporcionando bem-estar físico e mental. A proposta interprofissional caminha paralelamente à proposta do cuidado centrado no paciente.
Palavras-chave: Bioética. Assistência à saúde. Manejo da dor. Imperícia. Direitos humanos.

Resumen

Dolor y sufrimiento desde la perspectiva de la atención centrada en el paciente

El objetivo de esta reflexión es contribuir a la aplicación del cuidado centrado en el paciente en el tratamiento del dolor en un entorno hospitalario. Se trata de un estudio teórico que trata de estimular el debate sin agotar los argumentos, considerando cuestiones como las dimensiones del sufrimiento, la negligencia del dolor y sus consecuencias, la relevancia del abordaje interprofesional y los derechos humanos del paciente. Se concluye que es necesario contar con un equipo interprofesional que pueda lidiar con el dolor y el sufrimiento humano en el contexto de un hospital, considerando que la planificación de la asistencia debe tener en cuenta aspectos emocionales, económicos y culturales, proporcionando bienestar físico y mental. La propuesta interprofesional va de la mano con la propuesta de la atención centrada en el paciente.
Palabras clave: Bioética. Prestación de atención de salud. Manejo del dolor. Mala praxis. Derechos humanos.

The authors declare no conflict of interest.

While suffering is perceived as a vast, universal, existential feeling, pain can be described as a physiological process [1,2]. It can be either physical or emotional, related or not to an "actual" wound [3]. Its signifier comes from the Latin *poena*, usually defined in dictionaries as an *unpleasant or painful impression, resulting from some injury or abnormal state of the organism or part of it* [4].

According to Pessini, the International Association for the Study of Pain defines it as an *unpleasant sensory and emotional experience associated with real or potential injuries, or described as such injuries* [5]. Pain is the fifth of vital signs – the other four being pulse, breathing, temperature, and blood pressure – and one of the main factors of suffering [6]. It is directly related to quality of life and, depending on its severity, can lead those who suffer from it to beg for their death [1,7].

Pain and suffering undermine the body's integrity and the person's unity, yet they have been neglected in health care [1,7,8]. This negligence is all the more serious as it prevents enforcing human rights to promote patient-centered care. Such care would improve quality of care since collaboration arises from adapting professional actions to the patients' and their families' needs so that decisions can be taken together [9].

With that in mind, this theoretical study describes the dimensions of human pain and suffering, emphasizing the importance of an interprofessional team in its management; exposes the neglect of suffering, focusing on the ethical-professional issue; and, finally, proposes ways to promote patient-centered care.

Identifying the dimensions of pain and suffering

Human suffering goes beyond physiological factors. For example, when patients feel fragile, how they eat, move, and interact with themselves and with others changes. The mood is affected by illnesses, and many chronic patients even fall into depression [7]. Therefore, the patient's pain cannot be observed only through the biomedical perspective. It must be understood from an ethical point of view, considering its psychic, social, spiritual, and physical dimensions [10].

The psychic dimension goes back to mental health, to multiple high-complexity factors. Among various critical situations that may trigger this type of suffering, it is possible to highlight coping with pain in the terminal life process [1].

Social pain, on the other hand, is characterized by isolation in a given situation and the difficulty of communicating suffering [1]. It can be triggered by loss of role within the family organization, fear of separation, sense of abandonment, preemptive mourning, etc. In society, individuals are subject to different conditions (social, cultural, ethnic, gender) that influence how they experience and perceive pain [1,7,11].

Pain and suffering are experiences that must be more well defined. Although they often manifest as an individual and merely physical issue, they involve broader aspects. As socio-cultural experiences, pain, and suffering fit within determined times and contexts – rather than arising from social situations, they are part of historical processes [12].

There is also spirituality, an aspect that responds to human needs with potentially transforming beliefs. Pain can manifest itself through the loss of purpose and hopelessness of the individual who suffers. So, spirituality can improve the quality of life of those who seek comfort in the divine. A case report highlighted the influence of the sacred dimension in assessing intractable pain, refractory to pharmacological treatment [13].

In its physical dimension, pain arises as a result of injury, illness, or progressive deterioration that prevents optimal physiological functioning and indicates bodily dysfunction [1], and may be classified as acute or chronic.

Acute and chronic pain

Acute pain is the body's alert mechanism in response to mechanical, chemical, or thermal aggression; chronic pain causes organic imbalances that progressively decrease the person's functional capacities [2,14]. Acute pain is one of the main reasons people seek emergency services, being a valuable symptom in investigating and defining the patient's diagnosis [2].

The physiological typology forms of pain include somatic, visceral, and neuropathic. The first results from damage to the body surface, while the second is internal, as in abdominal cramps. Both are nociceptive: sensory experiences caused by the response of peripheral sensory neurons to acute harmful stimuli. Neuropathic pain, on the other hand, results from chronic dysfunction in the nervous system [14], and its treatment should

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consider neural blockade procedures and the use of tricyclic antidepressants [15].

Acute pain begins with objective and subjective physical signs associated with exaggerated activity within the nervous system. Endogenous substances are synthesized and released, stimulating nerve endings, as a result of traumatic conditions, infections, or inflammations. The main repercussions of unrelieved acute pain are tachycardia, arrhythmia, decreased tissue oxygenation, agitation, sweating, increased cardiac output (volume of blood pumped by the heart per minute), increased blood pressure and muscle contraction, bleeding, anxiety, and fear [16]. The natural evolution of pain is remission, but the prolonged activation of several neural pathways may lead it to change and become chronic [14].

Operative procedures, for example, cause acute trauma, with physiological and emotional changes that need to be adequately controlled. The immediate postoperative period comprises the first 24 hours after surgery and, during this time, discomfort and changes in the patient's metabolism are likely to occur [2]. Decreased sleep and appetite, dehydration, difficulty walking and moving around in bed, deep breathing or coughing, increased length of hospital stay, and thromboembolic and infectious risks are some of the complications triggered in this scenario [16]. Science treats the pathophysiology of chronic postoperative pain as a symptom transformation for a specific condition and, thus, should raise awareness regarding immediate and effective prevention and control practices among health professionals [8].

Chronic pain is continuous, and the nervous system gradually adapts to it. Objective signs are usually absent in patients suffering from this kind of pain, but there are evident changes in personality, lifestyle, and functional ability [1] – physical activity, sexual life, mood, self-esteem, family relationships, work, and leisure may be changed in several ways [14,16]. Constant discomfort generates increasing suffering, as the patient tends to feel as a burden to their family members or caregivers [13].

It is common for terminally ill patients experiencing pain to mix suffering with guilt and fear of abandonment [7]. Understanding pain and its effects is essential for palliative care, which seeks to treat psychological and social causes and consequences [1,17]. The approach promotes the quality of life of patients and family members facing potentially lethal diseases, relieving physical, psychological, social, and spiritual suffering.

Irruptive, intense, and idiopathic pain unrelated to any determined analgesic protocol nor to bodily functions or movements is frequent in oncology, being considered intractable [15]. Patients, caregivers, and family members living with advanced cancer present physical and psychological symptoms related to the disease and frequently get involved in discussions regarding care preferences [17]. Several randomized studies demonstrate that the involvement of these agents in palliative care during outpatient care contributes to positive outcomes [17]. Palliative care improves the patient's quality of life, mood, prognosis perception, and communication of preferences. Lower depression rates among caregivers and family members are also described.

Such care is related to orthothanasia – natural and dignified death, taking place at the "right time" –, which may occur when the end of life is imminent, with no chance of cure. This approach excludes medical-hospital interventionism, limiting itself to procedures intended to alleviate pain and suffering. In orthothanasia, death is understood as a natural process, it must respect the dignity of the human person [18].

Proper pain management can minimize and eliminate discomfort, facilitating the patient's recovery, preventing side-effects, and decreasing treatment costs; complications that intensify morbidity can also be avoided [16,17,19,20]. In palliative medicine, the approach adopted by the health professional must be based on support and care, aiming to relieve the patient's suffering at a time characterized by great discomfort, anguish, uncertainty, and even agony [18,19].

Neglect of pain and suffering in the hospital environment

Pain and the somatic and psychological changes it causes are related to morbidity and mortality in the hospital environment. Algic complaints are usually addressed late and inefficiently, which constitutes a clear neglect in physical, emotional, and social care [8]. Simões [15] reports that millions of people around the world suffer from some type of pain triggered by lack of or insufficient treatment. The author estimates that 70% to 80% of cancer patients experience moderate to severe pain, many dying without it being effectively managed. According to Simões, it would be possible to completely control it in 80% of cases, and there is enough evidence to promote excellent care in these situations.

The literature underlines the professionals' difficulty in managing pain and suffering, which involves ignorance about their real impact on the patients' health [8]. Several interventions have proven effective in preventing, controlling and relieving pain, such as the use of specific analgesics, innovative techniques in anesthesiology, devices for administering medications, performance protocols, and specific units [15].

Neglect is characterized by the lack of attention to any specific circumstance, given the professional's failure to aid. Pain causes physical, psychological, and social complications [1,15,16], whose neglect constitutes an ethical infraction liable for punishment. Health professions deontology deals with this moral premise.

The Brazilian Psychologist's Code of Professional Ethics [21] prohibits acts characterizing negligence, violence, or cruelty, whether performed by the professionals themselves or with their consent. As a result, the psychologist must observe the patient's subjective processes without disregarding somatic manifestations [21]. Social psychology, for example, must focus on living conditions and the context in which individuals are inserted. Feelings such as humiliation, shame, fear, and guilt have specific social causes that may trigger intense forms of suffering [22].

The Brazilian Nursing Professionals Code of Ethics [23] highlights human rights and the importance of communicating information in a clear and reliable manner, respecting the patient's autonomy throughout the life cycle and death process. The document also emphasizes that the professional cannot be conniving with any form of negligence, whether practiced individually or by the health team.

The Medical Code of Ethics [24] recommends that the patient be valued as a citizen with rights and duties, emphasizing the professional's responsibility to inform about existing treatment and options, as well as possible complications and risks. It is forbidden to cause any kind of damage, either by harmful action or by omission, characterized as malpractice, recklessness or negligence.

In the face of possible negligence in care, the deontological codes state the need to assess whether the conduct is intentional or if other circumstances beyond the professional's capabilities may have prevented the proper exercise of their functions. Only then can the necessary penalties be defined.

Souza and collaborators [25] assert that patients suffering from pain may have reduced autonomy. This occurs when the person is denied the right to choose between the available treatments or be informed about the painful experience and its management, ignoring their active participation in the therapy. This is a frequent situation, as patients tend to agree with the medical team while in the hospital environment. To avoid this scenario, hospitals must encourage the individual's autonomy, with further concern to their complaints and opinions [9,26].

Interprofessional team and pain management

Health professionals live with suffering, and pain management is one of their main duties within the hospital environment [1]. Providing analgesia to the patient and monitoring the evolution of the clinical picture should not be mechanical activities, but rather make the environment more humane [1,7]. Therefore, individualized treatment based on scientific evidence should be offered in addition to meticulously evaluating interventions to be performed. Preserving ethical values that support the quality of life of frail people is a crucial factor for the practice of interdisciplinary teams [27].

Barr [28] states that the precepts of comprehensive care are strongly associated with the interaction between professionals from different health fields and areas of knowledge. Approaches based on this interaction have been developed, such as complementary or alternative medicine, whose therapies use traditional knowledge to relieve pain and suffering. Similarly, Otis-Green and collaborators [29] propose a pain management model that integrates several professionals: psychologists, nurses, oncologists, psychiatrists, and social and religious workers.

The interprofessional movement thrives where conditions are favorable, when there is openness to dialogue and mutual support in the workplace, when there is a recognized need to improve assistance, and when the topic is discussed democratically between different areas in universities, with a critical positioning towards corporatism [28].

In Denmark, for example, interprofessional collaboration dates back to the early 1960s and is described in deontological regulations [28]. In Canada, the first initiative in this regard also dates from the 1960s, at the University of British Columbia, when it was proposed that health and social care professionals should be taught by the same professors. But

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due to the lack of support and changes in course regulations, the project was unsuccessful. In 2010, with the creation of the Canadian Interprofessional Health Collaborative and the Accreditation of Interprofessional Health Education, the institutions promoting interprofessional education in the country organized themselves. Standards and basic principles enshrined in a guide were formulated after extensive consultations [30].

In the interprofessional approach to health, everyone should have the same objectives, working together towards a common result: the recovery or improvement of the patient's quality of life [20]. It is essential to ensure the agreement between the methods used and effective communication on the benefits and harms of each decision [12]. Therefore, it is extremely important to establish teams that understand the complexity of pain and suffering.

Measuring pain in the hospital environment

Discerning the particularities of pain allows investigating its causes and identifying the best treatments [3,19]. Within the hospital context, different methods are currently used to assess the type and intensity of pain, represented by one– or multidimensional scales [19,31].

An example of a one-dimensional scale is the numerical estimation, in which the patient evaluates the pain by classifiying it from 0 to 10 (where 0 means "no pain," and 10, "unbearable pain"). Other examples are the visual analog scale, which uses a straight line to measure the level of discomfort, and the verbal scale, in which patients express themselves verbally. There is also the face scale, which uses facial expressions [19,32].

Multidimensional scales use graphical representation to locate pain across body regions. The McGill Questionnaire assesses the sensory, evaluative, and affective spheres, while the Pain Perception Record uses psychophysical techniques to quantify pain [19,32].

Measuring pain is a big challenge, and scales should be applied carefully to avoid ineffective treatments. Also, demystifying pain increases medicalization [33]. Each organism reacts differently to drugs and procedures, and cognitive and emotional aspects, as well as external factors, interfere in the recovery or exacerbation of pain [19,32]. Assistance, therefore, should be as individualized as possible.

Treatment depends on the clinical picture and type of pain. In acute cases, the goal is to reduce opioid analgesics and non-steroidal anti-inflammatory drugs dosage. In chronic pain, treatment is administered at regular intervals to prevent "pain memory," using additional doses of medication when necessary [34].

Complications of pain are related to underestimation, inadequate drug therapy (insufficient use of opioid analgesics, for example), unpreparedness of professionals, distorted beliefs and values concerning analgesia, and lack of systematization of evaluations [3,19,32]. Facing these obstacles is essential to combat the neglect of human suffering in health services. Qualified listening, sensitivity, respect, and empathy must be valued as a means to break the tendency of limiting attention to physical symptoms, as if they were the only possible root of the patient's anxieties [10].

Patient-centered care perspective

The biomedical therapeutic model evolved after the scientific revolution of the 19th century, becoming hegemonic during the 20th century. While it brought great scientific advances, it also gave doctors excessive power, making the diagnosis of the disease upstage the patient's perception. Technological development fragmented the idea of the body, dividing and subdividing medicine into ever smaller areas.

But if disease treatment may be impersonal, the same cannot be said about the care provided – it must be individualized. Contrary to the biomedical model, the biopsychosocial model took shape and began to consolidate itself among health professionals in the mid-twentieth century. According to this approach, the starting point of clinical care is the person, not the disease [34].

Patient-centered medicine transforms the traditional clinical model [35]. It advocates, for example, interpreting the disease based on the full understanding of the patient's experience, establishing common goals between professional and patient, adopting preventive and health promotion measures, and considering cost feasibility and duration of treatment. Its main advantages are an increase in patient and professional satisfaction, adherence to treatment, a lower number of complementary exams, and a decrease in referrals to other specialists, resulting in lower costs for the health care system and the patient [34,35].

Patient-centeredness is based on human rights [9]. Under this framework, the sick person is the main agent of the therapeutic procedure, and their participation is decisive for the desired

result. Rights such as private life non-disclosure and free consent must be respected – under the health care perspective, the patient's human rights differ from the patient's rights. The former are provided by legal rules of a binding nature, while the others are present in statements without legal obligation, but which recognize the centrality of the patient in the treatment.

The Institute of Medicine of the United States classified patient-centered care as one of the fundamental objectives of the health system [36]. According to Shaller [36], the literature is consensual regarding the main attributes of this type of assistance: education and shared knowledge; family and friends involvement; team collaboration; sensitivity to non-medical and spiritual dimensions; respect for the patient's needs and preferences; and free flow and access to information. Patient-centered care starts from the premise that neglect human suffering is unacceptable, morally justifying the respect for the patient's preferences.

Some questions may encourage participation: "Did I help you comprehend everything you need to understand about your illness?"; "Could you repeat what you understand?"; "Can I help you clarify the proposed treatment?" [37]. In this interaction, the patient is welcomed as the one with the best judgment. However, this premise is questionable, for example, when patients believe they require medication or specific therapy which is inappropriate or contraindicated. Accepting requests for unnecessary treatment means that the physician's conduct is not patient-centered [37].

Structural modifications, such as advanced access to digital health information records and scheduling, may assist health care in abiding 21st-century requirements, but should not be treated as patient-centered care. Simply implementing digital medical records does not constitute such assistance unless it promotes communication with the patient and their participation [37].

Participation tends to be lower among the least educated. Thus, patients need to be trained to engage in health care and its evaluation. This stimulus opposes professional paternalism and seeks to make accessible knowledge previously centered in an asymmetric dialogue [37].

Leadership and feedback are contributing factors to patient-centered care. Leadership is considered the most important, as organizational changes depend on institutional support. In turn, feedback from patients and families through surveys assessing health services should be used to improve quality of care [36].

In conclusion, the response to the neglect of pain and suffering in the hospital environment expresses respect for the patient's human rights, through effective communication [18,26,38], meeting the assumptions of interprofessionality [28]. For the minimum necessary to respect human dignity is perceiving each person as unique.

Final considerations

Pain must be understood in its psychic, social, spiritual, and physical dimensions. The person who suffers from it has the right to adequate treatment, respecting their individual assessment, and the health service must be able to identify needs through qualified listening, valuing the patient's and family members' perceptions.

As stated by Fernandes, Veríssimo, and Gama*, in addition to the difficult answer to the question of "why" there is pain/suffering, solidary care, which combines technical-scientific and human competence,* (…) *constitutes a valuable opportunity to* (…) *access our sensitivity and humanize ourselves in this process* [39]. We must analyze the neglect of pain and suffering and the role of the health professional from the perspective of deontological codes, using human rights as a reference to reinforce medical practices aimed at patient-centered care.

A holistic view of the patient affected by pain and suffering is required. Care planning must comprise emotional, economic, and cultural aspects, providing physical and mental well-being. The interprofessional proposal walks side by side with the centered care proposal: although the good professional-patient relationship may not, in itself, ensure the absence of neglect in care, there is no denying that dialogue and awareness of different points of view are fundamental [38].

The patient became the core of the discussions on health care quality. As Epstein and Street Junior [37] show, there have been concerns about a possible disagreement between the focus on individual needs and evidence-based medicine. However, this discussion seems to have reached a conclusion with the acceptance of the good results of the individual approach, given that both strands combine the science of generalization with the science of particularity.

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Participation of the authors

Marcelo Moreira Corgozinho conceived and revised the text. The other authors participated in the bibliographic review and wrote the original text. All authors reviewed the final version submitted for publication.

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