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THE MEANING OF PAIN IN THE EXPERIENCE OF A PERSON WITH ONCOLOGICAL PAIN

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ABSTRACT

Objective: to understand the meaning of pain in the experience of the person with oncological chronic pain.

Method: a qualitative nature methodology was used, with ten cancer patients followed in the consultation of the pain. The data collection instrument used was the partially structured interview and in the data analysis, phenomenology was used. The research was approved by the Ethics Committee of the Baixo Alentejo Local Health Unit.

Results: from the grouping of the units of signification, the central themes emerged as one of the themes: the meaning of pain, and from the grouping of the units of signification for this central theme, the following sub-theme was highlighted: description of pain.

Conclusion: the chronic pain of the oncological forum beyond a subjective and multidimensional experience is surely an individual experience, very particular, since the meaning of pain is unique for each person, since only the person who experiences it can describe.

Descriptors: Pain; oncology; patient; experience.

INTRODUCTION

This research is part of the course carried out in the scope of the Doctorate in Nursing Course, in which we aim to understand the meaning of pain in the experience of the person with cancer pain.

Over the centuries there have been several theories that have tried to explain what pain is. In ancient societies, pain, with no other apparent cause such as trauma, was attributed to the invasion of the body by evil spirits and punishment of the gods. Aristotle refers to the perception of pain as an emotion or passion of the soul and thus was described the theory of affections: "pain is an emotion, and its intensity depends on the meaning of the part involved, does not include the physiological aspects"[1]. Descartes rejects this theory defending the separation of body and soul by proposing the theory of specificity: "the messages of pain were carried in a certain transmission in a straight line, from receivers in a periphery to the brain"[1]. This theory does not involve the psychological aspects related to the perception of pain and the variability of responses, being the pain considered of degree equal to that of the lesion.

Subsequently, the theorists of standards emerged, arguing that people responded differently to the same stimulus, thus raising the theory of standards. All these theories, despite having great limitations, undoubtedly contributed to the understanding of the mechanisms of pain, and thus Melzack and Wall in 1965, based on the relationships between previous theories, proposed their gate theory as an important contribution to the understanding of the pain process by stating that pain is not a simple sensory experience but a complex integration of affective and cognitive sensory dimensions, and that the perception of pain and reactions to pain are not predictable, varying with each person and each experience[1].

Pain impulses are transmitted on fibers to the spinal cord via an open "path" in the gelatinous substance to the cerebral cortex, where pain perception and interpretation occur. This theory proposes that T cells (transmission cells) exist in the gelatinous substance, which facilitate the transmission of pain (opens the entrance) or inhibits this transmission (closes the entrance), thus intensifying or blocking the transmission of pain. The ease or inhibition of pain transmission depends on some factors, which will lead to different reactions to pain between people and even in the same person at different times, such as childhood experience, past experiences, cultural values, religious beliefs, age, attention and distraction, anxiety, personality, knowledge/understanding, tension and fear[1].

In this way, defining pain over time has not been easy given that it is a complex, subjective phenomenon of an individual experience and not directly observable. Currently the pain is defined as "anything, that the person who feels it says it is, existing whenever it says it exists"[1].

Chronic pain is associated with tissue destruction, has a longer existence, and the pains of patients with neoplasias may serve as an example. It causes prolonged and unbearable suffering, does not have a biological alert function and often generates physical, emotional and social stress, besides generating work incapacity, changes in sleep, appetite, affective life and mood changes, characterized mainly by the installation of depressive pictures[2].

Chronic pain then reveals itself as a multifaceted global pain described as "a multidimensional phenomenon, including not only a sensory dimension, but also physiological, affective, cognitive and behavioral dimensions that contribute to the experience of global pain"[3]. This is apparent in the study by Waterkemper R. and Reibnitz K.S. in which nurses "understand the pain in cancer as a total pain because it goes beyond the limit of the physical dimension"[4]. It can be said that chronic pain, being a multidimensional experience, leads to a rupture in the relation established with the world, since it does not

invade, lacerate, not only slaughter the body, invade, lacerate and slaughter the person and makes him indifferent to the events that take place around him. Take away the taste for everything. It withdraws, from the man, their old habits and forces them to live a life, in which they cannot find themselves in a kind of mourning for themselves"[2]. Chronic pain modifies the sick person's daily life, their relationships with others and ends up breaking their relationship with the world and, therefore, it also means suffering.

METHOD

Being the objective of this investigation, to understand the meaning of the pain in the experience of the person with chronic pain of the oncological forum, we opted for a method of qualitative research using the phenomenology, since it allows to study the phenomenon from the person's perceptions of reality, that is, of the meaning that the person attributes to the phenomenon.

An analysis of the descriptions of the person is made, and these are the source of data. This analysis consists of "penetrating the intentional meaning contained in the descriptive data"[5], in order to find their meanings, that is, the essence of the experience lived by the person.

A sample of ten patients was selected, from the total of those followed in the Day Hospital Service of the Baixo Alentejo Local Health Unit (ULSBA). The selection was made intentionally and involved the following inclusion criteria, defined by the investigator: to have oncological disease; be followed in consulting the pain; have their cognitive ability preserved (data obtained with the Mini Mental State test) and accept to participate in the study. The partially structured interview was used as a data collection instrument, and the data collection process was carried out in October and November 2010. The ten interviews carried out allowed us to arrive at data saturation and constitute the corpus of analysis of this study.

After the transcription of the interviews and the various readings and re-readings, the need is felt to use some symbols capable of helping to understand the non-verbal language expressed by the subjects of the study, with the intent of apprehending the whole of their discourse, beyond verbal message, because often "words do not come to the patient to express the total pain that is feeling and may not even use them, hence one must be aware of what the patient transmits in a non-verbal way, to better understand their pain[6].

Thus, in the units of signification transcribed, the expression of the gaze of suffering is represented by the symbol (), and the silences in the speeches of the participants, which accompany their expression of the look, are identified with the punctuation mark of three points ...

In the analysis of the data, the methodological path is followed, recommended by Deschamps that involves four distinct stages. The first one involves highlighting the overall meaning of the text, because through the various readings made in each of the interviews, this stage allowed the researcher to familiarize themselves with the experience narrated by the study participants. In the second phase of the analysis of the data, the units of signification were identified, the text being subdivided into units of natural meaning, that is, the units of meaning were identified through a spontaneous analysis of the researcher, having always maintained the full respect of the which was reported by the study subjects. Subsequently the units of meaning were grouped by content and emerged the central themes. The third stage of the data analysis refers to the development of the content of the units of signification. At this stage, the researcher in the analysis of the central themes deepened the understanding of the units of signification, and the central themes were later broken down into subtopics. The fourth phase is the last of the data analysis and comprises the synthesis of the set of units of signification. The researcher, through the meeting of the units of meaning in depth, made a consistent and coherent description that took a synthetic form, the latter stage consisting of three distinct operations: the description of the particular experience of each study participant, the description of the typical structure of the phenomenon, and the communication to others of the description of the structure[5].

The categorization process was put to the consideration of two investigative experts, in order to certify the fidelity of the data.

We then returned to the study participants to perform the validation of the descriptions, in order to ensure the validation of the results, and they were validated in their entirety.

In the field of ethical issues, the request for authorization was made to the Director of the Local Health Unit of Baixo Alentejo, as well as the opinion of the Ethics Committee of the said Health Unit, and we received authorization and approval to carry out the proposed research with the approval number 196. All participants in the study signed the Informed Consent Term, where the objectives of the research were exposed, as well as the guarantee of anonymity. Ethical procedures were also complied with as recommended by the Helsinki Declaration of Ethics in research involving human subjects[7].

RESULTS

During the analysis of the data, through the grouping of units of meaning by content, the central theme emerged: the meaning of pain. When analyzing the aforementioned central theme, the sub-theme was highlighted: description of pain. The identified sub-theme was approached with involvement and depth by the study participants, as they made the researcher understand and feel that the aspects that make up the sub-theme mentioned were extremely important and had a great impact on their lives.

The chronic pain of the oncological forum proved to be an intolerable and useless odious experience. Painful symptoms, disability, primarily related to neoplasia and its treatment, from vomiting, anorexia and asthenia, as well as loss of social life, reduction of professional and leisure activities, times, the will to live. Chronic pain then proved to be global, multifaceted pain. Because of the multidimensional nature of pain, "it is often useful to think in terms of total pain, which encompasses physical, psychological, social, and spiritual aspects"[8].

The pain produced repercussions of diverse natures, being essential "to have a holistic, multi, Inter and transdisciplinary vision of the human being as a whole, because to be a person is to possess a physical, mental and spiritual body"[9].

Chronic pain is "a subjective phenomenon, and can be indicated and quantified by the person who feels it"[10]. For the description of pain is always subjective to the hearer, because he does not experience the pain of the other. It is also an individual experience, since it is variable from person to person as to its perception, being the meaning of pain unique to each individual. Pain sensitivity is characterized by a great variability of expressions from person to person and even in the same person at different times. The patients described their pain as they felt it, for "[...] only those who feel can express it [...]"[9]. No one is better than the patient to describe the pain he feels, since it is only him that the experience, being the same "described as a unique and personal experience"[11]. In this way, "the subject who experiences pain is the expert on the pattern, location, intensity and nature of pain"[12], it is only he who can speak about it.

DISCUSSION

Pain description

It is not easy to define pain, since it is an individual experience, not directly observable, because only the person who experiences pain is able to speak of it. The person's description of his pain is subjective because we do not experience it, we do not feel it, we do not experience it in this sense. "In order to evaluate the pain experience, one must trust in the words and behavior of the patient [...]"[9], because "it is not the responsibility of the patient to prove that he is in pain, it is the responsibility of the nurse to accept the patient's report of pain"[13], without making judgments of value, and it is fundamental to believe in the pain that the sick person describes:

I had some pain I could not take, [...],here at the end of the spine, ... (),it looks like this area was ripped off. (E2).

They were very big pains, ... (),it seemed like everything was broken inside me. (E6).

[...]The pain was here in the arm, ... (),as if a constant bite. (E7).

Thus, a person's verbal description of their pain becomes extremely important in order to evaluate the pain. In the study carried out by Nobre, it was verified that the nurses perceived the patients' pain "through their verbal communication, that is, by their words, how they describe their pain"[6]. In our study, participants also continued to express their pain through words:

Pain is a bad thing, ... which often does not hold up. (E2).

[...]The pains are not seen, if they were seen, ... (), the pain is anything that does not work well and becomes painful. (E2).

It is a pain, ... that when I make some movement it comes like this by the back, sting is not continuous. When I breathe deeper, then she gives that signal, [...]. (E9).

But often the words do not come up to the person to express the total pain they are feeling and may not even use them, and it is fundamental that health professionals are attentive to what the person transmits either verbal or non-verbal, to better understand their pain. The language of the body speaks for us and often betrays us when we do not want to reveal ourselves. This language often expresses "[...] messages that complement

those conveyed by words, often contradicting what appeared on the surface through them"[14]. Nonverbal language "[...] is often as rich as verbal language. [...] is quite revealing of what the patient experiences, [...] "[14]. Because non-verbal language is the truest one, the one who does not know how to lie, it is because they are spontaneous. In the study conducted by Nobre, the study subjects reported that "they also perceive patients' pain through their non-verbal communication: expression of the look, facial expressions, body posture and tight touch"[6]. Still in Silva and Zago's study, participants also reported that they understand pain in the patient through the gaze: "we perceive chronic pain in the eyes of the patient [...] It seems that they transmit it with their eyes, asking for help: do something to ease my pain"[15]. Non-verbal communication involves a set of facial, body, and behavioral expressions that accompany and support verbal communication, since non-verbal language "reinforces, contradicts or colors verbal language. It is the non-verbal language that in most cases translates the states of soul related to the words heard. [...] they transmit, to us, the language of deep emotions"[14]. The nurse who has the capacity to listen is not only attentive to the verbal communication of the patient, but to everything that the patient is able to transmit in a nonverbal way, because "it is through listening to the nonverbal language that the nurse completes what they have heard through words, in order to better understand the patient "[14].

Pain can be manifested in various ways through crying, groaning, agitation, shouting or verbal behavior; however, the absence of these manifestations in the patient who remains silent does not mean the absence of pain, since some patients [...] can adapt to pain by developing a high self-control, suppressing the signs of suffering or just remaining prostrate [...] due to physical and mental exhaustion caused by the disease, [...]"[9].

In this study, during the interviews, special attention was paid to the verbal communication of the participants, but also to their non-verbal communication in order to better understand their experience of pain, namely through the expression of the look and the silences, as they undoubtedly offered, a significant quality to the content of the message expressed, reinforcing and completing it. It is often said that the eyes are the mirror of the soul, which means that in face-to-face communication much is said through the eye, which words cannot express. Some participants in this study, by their expression of the gaze, transmitted suffering through a dull look, directed downward, and frowning overlap. They thus let the suffering in which the chronic pain of the oncological forum plunged them. The expression of the gaze of suffering is represented in the units of signification transcribed through the symbol ().Silence is another aspect of the non-verbal language that needs to be attentive, it can mean "fear or suffering that prevents words from coming out, or a joy so intense that it cannot be explained by words. Silence can be

that of life which is inexorably extinguished, but also that which ceaselessly springs forth"[14]. In order to listen to silence, it is essential that the nurse is fully present, for "[...] he must fully offer his presence and his attention to the whole person of his patient [...]"[14] since listening, it is not just listening. To listen to the silence "[...] is to listen to what the other lives from deeper"[14]. Silence is full of meaning, for "... it may mean the integration of what has just been said. It can also translate the intensity of demand for the most relevant response, taking into account all that preceded it"[14]. In this study, the silences used by the participants followed their expression of the look and are represented in the units of signification transcribed through the symbol ...

The perception of pain and the reaction to pain are variable from person to person and sometimes in the same person at different times. Each one describes his pain as he feels it, according to his experience, because nobody is better than the person to describe the pain he feels, because it is the person who experiences it, then it is only he who can talk about it. Pain is "anything, that the person who feels it says it is, existing whenever it says it exists"[1]. In this way, the subjects of the study described their pain through verbal communication, that is, by their words, and non-verbal communication, namely through the expression of the look and the silences:

Pain is something that saddens us, suffers ... (), takes away the will of everything, [...]. (E1).

[...]It's a horrible thing ... (), that you cannot tell what it is, every person is what do you feel, [...]. (E5).

[...]It's something you do not see ... (), the one who has the pain is the one who knows how to talk about them. (E5).

Pain can be classified into acute and chronic pain. Oncologic pain is part of the concept of chronic pain, in which a sense of helplessness, despair and absurdity invades the sick:

Sometimes they are terrible pains, I cannot take it, I feel bad, ..., it's an aggressive pain, a pain ... (), I even know the sign of pain, when it comes stronger, [...]. (E2).

[...]It's almost unbearable, that pain ... (), turns out to be a bit disabling. (E8).

Chronic pain overwhelms, depletes, discourages and despairs the sick, prolongs itself in time, becomes obnoxious, unbearable, and has no biological alert function. More than a symptom, it becomes a disease:

I have had very strong, unbearable pains that take away all the will ... (), it is great suffering is not being able to do things from day to day. (E3).

The pain [...] appears so suddenly and causes suffering ... (), it is a bad thing that does not let us be okay, [...]. (E5).

It's a horrible thing, I cannot explain ... (), you cannot see ... you cannot see it, but it's a horrible thing, [...]. (E7).

The chronic pain of the oncological forum dominates the life and the worries of the patient, since it is associated to the incapacities dictated by the disease itself and by the treatments, which introduces limitations not only physically, but also to the psychological, labor, social, familiar levels and spiritual:

[...]I see myself very upset, sad to want to do my things and cannot.
One passes the life with the pain ... (), with sadness many days, is thus [...]. (E1).

It is something that is bad for the person because the person does not feel well, cannot do things from day to day ... (), [...]. (E2).

I could not sleep, I could not even get up, if II could get up, [...] they had to help me, I could not because of the pain ... (), [...]. (E6).

In the study carried out by González-Rendón and Moreno-Monsiváis, it was verified that "... the functional incapacitation caused by pain is a cause of suffering in the patients, their families and the people close to them"[16]. Similarly, the patients in our study had several changes, ranging from decreased mobility, difficulty or inability to perform an activity:

[...]I cannot shop, I cannot clean my house, I cannot do cleaning such as washing a floor, cleaning the dust, [...]. I do not have the strength ...(), I feel no strength, [...]. (E1).

Physical pain will not let me iron, vacuum the house, will not let me do movements, efforts. (E3).

[...]I could not get up or shower alone, it had to be my husband to help me in everything, [...]. (E6).

Chronic pain is a subjective sensation that affects not only the physical dimension, but also the psychological and spiritual dimensions, and leads to social and family isolation, to the loss of social life, thus described this participant referring to pain:

It is something that saddens us, suffers ... (), takes the will of everything, even of talk to other people, I just feel like being alone, [...]. (E1).

Reducing domestic, occupational, social and leisure activities often deprives the patient of the will to live:

" [...]I stopped doing everything, housework, going out to the café, working, isolating myself ...,I had depression, I'm still doing treatments ... (), [...], I still thought of ending my life." (E3).

It can be said that the chronic pain of the oncological forum besides translating a subjective and individual experience, also entails a multi-dimensionality, causing incapacities, compromising quality of life and generating immeasurable economic and psychosocial repercussions. For beyond the physical dimension to be affected, so are the dimensions: social, psychological and spiritual, taking the designation of total pain:

I've had a lot of pain in my leg, and then it's the other pain ... from the other side everywhere, here, there, there ... (), everything hurts, from the body to the lack of will, to the sadness ..., [...]. (E1).

The pain can be physical and psychological. (E3).

The psychological pain is different, I can make the efforts, but I do not feel like it, I do not feel like doing them. (E3).

The study by González-Rendón and Moreno-Monsiváis revealed that pain "[...] can have serious adverse effects on patients' physical, psychological, emotional, social and spiritual state, which is reflected in daily and daily life activities and conditions economic, labor and social losses"[16]. In this study, in the person with chronic oncologic pain, the alterations, the losses that arose in both the physical and psychological dimensions, but also in the social and spiritual dimensions, contributed to exacerbate the pain and made it possible to understand it as total pain. For the changes occurring in the various dimensions lead to increased pain perception and consequently cooperate for the continuation of new alterations and other losses at various levels, repeatedly translating into an increase in pain perception, and so on. This cycle often leads to depressive states. Chronic pain then reveals itself as a global pain, multifaceted. It becomes a total pain, in which everything is pain and, as it is said, even the soul hurts:

[...]Hair loss is a thing that is a bit painful ..., these things hurtvery ... (), but it's a pain that does not go with pills, [...]. (E4).

[...]The pain is more psychological than physical, I think it hurts more to think, I know that, it hurts me here, I have pain here, but I think it affects me more psychologically ... (), this messes with everything ..., [...]. (E10).

The person with chronic oncological pain "needs to be assisted in its entirety, and the Nursing actions must seek the balance, between the maintenance of the physical, emotional and social functions"[17]. Because oncological pain, when it becomes a disease in itself, represents one of the most painful experiences for the patient and for all who live with him, including the multidimensional nature of pain, poses a particular challenge to all health professionals responsible for their limits and their incapacities, so they must add knowledge to care for these patients, "knowing the different types of treatment and possible ways of managing them, in order to contribute to patient support in search for comprehensive and safe care"[18]. In this context, it is essential the intervention of a multidisciplinary team capable of responding to the changes that occur not only in the physical dimension of the person with cancer pain but also in their psychological, social and spiritual dimensions.

CONCLUSIONS

The body itself produces the language of pain, from the frowning of the eyebrow, to the body posture of defense, to groaning, to crying, to tears, to silence, and even to pronounced words about pain. These are languages, both verbal and non-verbal, recognizable to each other's gaze, because the pain is directed at the other. Pain seeks listening, seeks contact, touch and words, a language that contains it and that makes it bearable. Pain exists when and where the person feels it, is known as one of the most common symptoms in the context of diseases and involves man from the beginnings of mankind. It is an eminently subjective experience that in addition to sensation, is also perception varied by the personality of those who suffer it.

In this study, it was confirmed that pain is an individual experience since the meaning of pain is unique to each person. The person with chronic pain of the oncological forum speaks of their pain, describes it in the way they feel it and experience it in their daily lives, and consolidates the idea that pain, apart from being a subjective experience, is, without doubt, an individual experience, very peculiar, since only the person who experiences it can describe. It was also found that the person with cancer pain expresses pain not only through words but also through their nonverbal manifestations, from the expression of the gaze, silence, facial expression and body posture. These are the nonverbal manifestations that usually reinforce the verbalizations made, but also can contradict the same in situations in which the patient omits their pain verbally. It was also verified that cancer pain promotes changes in the sick person at various levels, because

it involves not only the physical dimension, but also the psychological, social and spiritual dimensions. Losses arising in the various dimensions tend to exacerbate pain, and increased pain perception leads to further losses and, consequently, to a new increase in pain perception, and so on. Pain thus assumes its multidimensionality.

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