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THE EXPERIENCE OF THE PERSON WITH ONCOLOGICAL PAIN IN ITS TRANSCENDENCE

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ABSTRACT

Objective: understanding the person with chronic and oncologic pain experience in its transcendence.

Method: qualitative methodology, using phenomenology. The study participants were ten oncologic patients, accompanied on the pain medical consult and as an instrument for data collection, we developed partially structured interviews.

Results: after the signification unities organization, originated by the interviews procedure, the central thematics emerged, being one of them: transcendence on the person with chronic and oncologic pain experience. Through the signification unities organization for this central thematic, the following sub-thematics were identified: hope and inner strength and faith.

Conclusion: hope is perceived as an inner strenght which leads to positive thinking. The faith when believing in the transcendent or divine is felt as comfort, as a source of support or a sharing possibility.

Descriptors: Hope; faith healing; medical oncology.

INTRODUCTION

This research reproduces a part of the path taken in the scope of the Doctorate in Nursing Course, in which the aim is to understand the experience of the person with chronic pain of the oncological forum in its transcendence.

Spirituality is part of human nature and is relevant at the moment of transcendence, since it encompasses the existential domain, the essence of life, the values of the human being and the sense that the same attributes to his life, seeking an answer for the events, for integrity, peace, happiness, hope and individuality. The dimension of spirituality becomes exalted and assumes relevance in situations of emotional stress, physical illness, in the proximity of death, in the face of adversity of life, such as the person with chronic pain of the oncological forum.

Spirituality and religiosity are terms that complement each other, but not synonyms. Spirituality has a broader and more personal concept, "it is related to a set of intimate values, inner completeness, harmony, connection with others; stimulates an interest in others and by themselves; a unity with life, nature and the universe"⁽¹⁾. Spirituality is inherent to the human being, that is, we all have spirituality but not all of us have religiosity, because religiosity refers to a system of structured beliefs capable of answering

spiritual questions, i.e. it involves what the person follows, in a doctrine of spiritual and moral values and principles, shared by people in a community, and it also consists in the search for a relationship with a higher being, revered through scriptures, prayers, songs and dances⁽²⁾.

It can be said that spirituality is characterized by a dimension of depth, which seeks to answer the questions of the meaning of life, the meaning of death, suffering, joy, the choices that are made in life, as well as the "capacity to see beyond the present circumstances that allows the person to guide his life and to overcome the difficulties"⁽³⁾.

Patients, in addition to physical pain, "experience other, much more complex and profound pains that refer to the meaning of life and death"⁽⁴⁾, hope and inner strength, and faith, accompany them daily, since hope is seen as a possible way out of the cycle of pain and suffering and experienced as a comfort, because "hope is assigned a therapeutic power: being stronger than optimism, is an important coping mechanism that influences physical, emotional, and spiritual well-being"⁽³⁾. One of the attributes of the process of hope involves the existence of an inner force, which is the essential characteristic for hope to occur, for there is no hope without there being an inner force. We can say that hope can be the spark that moves the man in the direction of seeking help, because it is something that cannot be touched or seen, but that has the power to support us in some of the most difficult moments of life.

Faith is sustained by hope, because hope characterizes the state of spirit that accompanies the faith, which is conceived as comfort, as a source of support and possibility of sharing with the transcendent or the divine, which enables the sick person not to be feeling alone and, at the same time, allows him to reduce anxiety, fears, but also to gain confidence and to believe, since "one of the ways of coping with sickness and death is directly linked to the strength of faith"⁽¹⁾.

METHOD

Since this study aimed to understand the meaning of the experience lived by the person with chronic pain of the oncological forum in its transcendence, we chose a qualitative research method using phenomenology from the perspective of Martin Heidegger. The fundamental question of Heidegger's philosophy is not man but the Being, the sense of Being, since the Heideggerian method makes possible to arrive at the understanding of the Being, through the description of the situations that the individuals experience⁽⁵⁾.

The phenomenological approach allows to study the phenomenon from the meaning that it has for the person, identifying the perceptions that it has of the reality looking for the individual particularities, the meanings and the experiences of that person and are its descriptions that constitute the source of data, through a descriptive analysis of the meanings of language. According to Deschamps, this analysis consists of "penetrating the intentional meaning contained in the descriptive data"⁽⁶⁾, in order to discover in them the essence of the experience lived by the person.

A sample of ten patients, six of whom were female, aged 44-76 years, were selected from the total number of patients followed at the Day Hospital Service of the Baixo Alentejo Local Health Unit (EPE), which obeyed the inclusion criteria defined by the investigator, being the same: to have oncological disease, to be followed in the consultation of the pain, to have preserved their cognitive capacity (data obtained with the Mini Mental State test) and to accept to participate in the study. The selection was made intentionally because "the logic and power of the intentional sample lies in the selection of rich cases of information to study in depth"⁽⁷⁾.

As a data collection instrument the partially structured interview was used. The data collection process was carried out in October and November 2010. The ten interviews allowed data to be saturated.

After conducting the interviews and their transcription, we have made several readings and re-readings of them, and to better understand the entire discourse of the study subjects, in addition to the verbal message, we chose to use some symbols capable of facilitating the understanding of the language non-verbal expression expressed by them. In this way, in the units of signification transcribed, the expression of the look of suffering through the symbol () and the expression of the look of hope with the symbol (-) is represented. The silences in participants' speeches accompany their expression of the look and are identified with the punctuation mark of three points ...

We went on to analyze the data, where we proceeded to the different stages of the phenomenological reduction. We follow the methodological approach recommended by Deschamps, which consists of four stages: the first step involves highlighting the overall meaning of the text, as it allowed the researcher to enter into the text content and become familiar with the experience reported by the study participants, through the various readings of each of the interviews. The second phase of the data analysis concerns the identification of units of meaning, in which the text was subdivided into natural units of meaning, meaning the units of meaning were identified through a spontaneous analysis of the researcher, in full respect of what was said by the study subjects. In this

way, after the grouping of the units of meaning by contents, the central themes emerged. The third stage of the data analysis refers to the development of the content of the units of signification, in which the investigator deepened the understanding of the units of signification in the analysis of the central themes, and the central themes were broken down into subtopics. The fourth and last phase of the analysis of a phenomenological study involves the synthesis of the set of units of signification, here the investigator brought together the units of meaning in depth into a consistent and coherent description, which took a synthetic form. This last stage is composed of three distinct operations: a description of the particular experience of each participant in the study, a description of the typical structure of the phenomenon, and communication to others of the description of the structure⁽⁶⁾.

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

We later returned to the study participants to validate the descriptions, in order to ensure the validation of the results, all of which were validated.

With regard to ethical issues, we requested the authorization of the Director of the Local Health Unit of Baixo Alentejo, EPE where the study was conducted, as well as the opinion of the Ethics Committee of the Health Unit mentioned above, and we obtained authorization and approval for the execution of the proposed research with approval number 196. All the participants of the study were asked to present the Free and Informed Consent Form, which stated the objectives of the research and the guarantee of anonymity. All ethical procedures were followed as recommended by the Helsinki Declaration of Ethics in research involving human subjects⁽⁸⁾.

RESULTS

The results presented are a cross-section of the themes and sub-themes identified in the research carried out under the PhD Course in Nursing. During the analysis of the data, through the grouping of units of meaning by content, the central theme emerged: transcendence in the experience of the person with chronic pain of the oncological forum. In analyzing this central theme, it was decomposed into two sub-themes, namely, "hope and inner strength," and "faith." The identified subtopics were approached with involvement and depth by the study participants, as they made the researcher understand and feel that the aspects that make up the mentioned subtopics were extremely important and had a great impact on their lives:

Hope and inner strength

Faced with the different adversities of life, hope always remains and focuses on the possibility of overcoming the present situation, that is, overcoming another stage, just as other difficulties and setbacks were previously overcome, since one of the attributes of the hope process involves the existence of an inner force, which is fundamental for hope to happen. For the subjects of our study, hope translates into an inner and dynamic force:

[...]Now is the time, I have the willpower. (E2)

[...]Go forward because you have to face yourself this way. (E4)

[...]I have the support of my partner, my family, but the greatest strength comes from ourselves. (E3)

Participants in the study speak about the importance of inner strength, their ability to drive positive thinking, help overcome the new stages, and overcome the present situation:

[...]I try to have a positive thinking, I write several sheets with the phrase: I am cured, and I spread through the house, it is a way of going inside, head, what I really want, because everything goes on in our head." (E3)

[...]I am optimistic by nature, I have always been throughout life and now this is another step that I hope to win. This is precisely the force that gives me. (E9)

[...]Now I have been very positive, so I do not want to download, I want to overcome this ... (-), it is this force that I feel. (E10)

Spirituality involves the deep dimension of oneself, it translates into a work of inner search that allows to increase the knowledge and inner growth, leading to the enrichment of being.

Hope in the person with chronic pain of the oncological forum always remains, since listening to our patients, which always impressed us, was that even the most conformed, the most realistic, left open the possibility of some cure, a new product discovered, or a recent research project succeeding. What sustains them through the days, weeks or months of suffering is this thread of hope⁽⁹⁾.

Thus, it refers to one of the participants of our study:

[...]then we are always with that hope ..., of things improve a little, when the head is a little fresher we think a little more of the good side." (E1)

In this sense, it is important to listen to the hope of the person with chronic cancer pain and to provide well-being, by maintaining and adjusting the hope without maximizing or minimizing it, only helping the patient achieve his goals and supporting the new goals set by the patient, because as the disease situation progresses and the limitations progress, it is the patient himself who aims at his hopes, his goals. We can thus say that the patient's hope is always maintained, but is transformed by the limitations imposed by the progression of the illness, that is, "the hope no longer means the desire for something different and adapts to the real possibilities"⁽³⁾.

It is essential to maintain and support the hope of the sick person or to encourage possible paths of hope, as well as to help the patient define and redefine his goals and to achieve them, because "hope has to have a goal. Sometimes it is necessary to transform a final goal (probably unrealistic) into a series of (more realistic) mini-goals"⁽¹⁰⁾. In our study, the objectives defined by some of the participants could be considered final objectives, such as the possibility of accompanying the future of nephews, children and grandchildren:

[...]I struggle every day because I have to have strength, I have to fight to continue living ... I do not want to die yet ... (--),I do not have children, but I have five nephews and nieces, and I would love to see their future, the children they will have, follow their lives longer, I cling to it ... (-), that's why I fight. (E3)

[...]I clung to life and I think I still have the age to at least raise my children, I have to leave my children raised ... (-), it is my strength. (E4)

[...]I try to react because I have five grandchildren and I like to see them oriented, I would like to see their future, the life they will have ... (-), that's why I try to react. (E5)

Another of the subjects of the study outlines more concrete, more realistic objectives, and places their hope and confidence in the treatments of chemotherapy:

[...]But I am not discouraged by the situation either, because I am hopeful that I get to the end of the chemotherapy and the thing starts to improve, and I start to make a more normal life. (E8)

For some patients in our study, hope means the desire for the possibility of healing and for continuing with the life they had previously. Sometimes, in the situation of the person with chronic oncologic pain, the need to hold hope is comparable to the fear of being deceived, because hope is confused and ambiguous as treatments fail and disease progresses, and we are torn between the need to maintain hope and fight with all possible means for our survival, and fear (equally powerful and profound) that reality will again disappoint us⁽³⁾.

Patients anticipate daily, the fear of the treatments failing and everything (of the whole process) has to start over, so one study participant reports:

[...]When I learned that the first treatments did not work out, it was another shock, it's as if they told me that I had another ... (), and now I'm afraid of having to go through it all again. (E7)

[...]I'm always thinking about this and I'm afraid this second treatment will not work, from going back to the beginning ... (), I'm afraid. (E7).

As the condition of the patient worsens, hope is directed towards a new awareness and inner growth of the sick person, for "we can change the hope of living but for the hope of living in a more valuable way"⁽³⁾. This perspective raises the question of:

if we can expect something good in the future when there is no possibility of a cure. The answer is yes. There is hope and there is hope at different levels. We can expect to be taken into account as persons [...] that the time remaining can be full of meaning and affection... a time when we can feel accompanied, loved and respected ... We hope we can mean something to others⁽³⁾.

We can say that in spite of or through suffering it is possible to grow personally and spiritually, for "when there is little to be expected, it is still realistic to hope for a serene death"⁽¹⁰⁾. There are people who face the end of life or situations of great suffering let themselves go, surrender themselves, give themselves to their destiny. They walk a path where they confront each other simultaneously, with lucidity and hope, and with the acceptance of death and life. At bottom, it is a question of becoming aware of its finitude in front of life, but with greater acuity:

[...]What I think is to go on living like this until God takes me, I think I'm going to do these treatments until I put up with it, and if I do not put up with them, I'll stop them until it's over ... (), it's like life, go as God intended. (E1)

In this way, hope "tends to focus more on Being than on conquering; in relationships with others; in relationship with God or with a higher entity"⁽¹⁰⁾.

It is, without doubt, the hope that enables patients with chronic cancer pain to continue on their path. The human-therapeutic factor, more importantly, translates into the capacity for effort to instill hope. Because, hope is a constitutive of human existence that transcends mere optimism in situations such as that of the person with chronic pain of the oncological forum.

Faith

In the person with chronic oncological pain, faith relates to hope, is conceived as comfort, as a source of support and enables one to believe in something positive. The faith related to the transcendent or the divine is based on the sharing of doubts, worries and anxieties on the part of the patient, which contributes to diminish their anxiety, fears and sustain hope:

[...]I have faith with Our Lady of Fatima, I am always asking for your help ... (-), I have faith. (E7)

The study participants continue to point out, in their accounts, the connection between faith and the transcendent or the divine:

[...]I go to church and ask God a lot, maybe it's my way of thinking, I have a lot of faith ... (-), and then while I'm here I'm going to live one day at a time. (E6)

[...]I'm going to Mass, The priest has already given a Mass for me, for my improvements. (E6)

Prayer is also a form of communication and can be used by the sick person because it gives confidence and is often related to the decrease of anxiety⁽¹¹⁾. Religious practice is part of the spirituality of the person and favors the ability to face and accept adversity. Our study finds that the participants perceive faith linked to hope, present in their daily experience, which makes believe something positive, based on a transcendental belief:

[...]God is everywhere and there is, and we have to have faith ... (-), I have faith. (E9)

[...]I'm here until God wants me, I'll only leave when he wants. I have great faith, I am a believer, I believe that God can help me to overcome all this or to accompany me to the end, whatever he wants. I've already spoken to God, I went to the edge of a river, sat down, looked at the heavens and said, "God ... I accept whatever you have for me ... (-), but it's still early to leave. (E3)

Belief in a superior and/or inner force means to see in the human being the quality of transcendence, which goes beyond the physical body and permeates the realm of subjectivity and connectivity, with God, with others, with nature and with oneself⁽¹²⁾, so it is verified in the subjects of our study:

[...]I am a person of faith, my faith is that it is guiding me, I have faith that comes to the end of the treatment and that it gets a lot better, I do not know if this gives to clean totally, but that happens to make my normal life, like I was doing this far. (E8)

[...]Even before I was a person of faith, because things happened to me in life that actually ... (-), faith is what helped, with faith I have overcome all this, thank God, I put everything in the hand of God. (E9)

Faith in allowing sharing with the transcendent or the divine helps to lessen anxiety, to gain confidence, to believe, to have inner strength, and to develop positive thinking.

DISCUSSION

We know that there is no hope without there being an inner strength, which is the essential characteristic for hope to occur. Patients with chronic cancer pain always maintain hope, which translates into an inner strength capable of stimulating positive thinking and transcending the here and now.

Hope changes, according to the progress of the disease, and, consequently, changes in the various dimensions, because, "in the course of the disease, there is often a gradual transformation of hope and, in some cases, transformation in the quality of the same"⁽³⁾, and the patient himself to limit their goals, while tracing increasingly concrete goals.

Sometimes the patient's hope may seem unrealistic from the point of view of health professionals, but it may not be hoped for in the perspective of the sick person. "Hope is mobilizing efforts, energy so that nurse and patient in a concerted action move toward a common goal"⁽¹³⁾. In this way, to accompany the patients in hope requires interior closeness, to walk beside them and to serve them as support, developing attitudes of help and internalizing them, through the word and non-verbal language: from the silent and eloquent presence of the professional health, your posture, your smile and the look, that is, the powerful language of gestures. This language of the body is all the more important when words can no longer be said. In this context, according to Bermejo, the health professional feels called to be a man of hope at a crossroads of suffering and obscurity, a hope that allows us to look beyond the satisfaction of immediate desires, even beyond pain and death, when the anthropological vision does not end with death, and when the patient manifests a transcendent vision⁽¹⁴⁾.

Hope and faith help the sick person to face, accept and overcome the adversities of life, assist in maintaining control of difficult situations by providing security and optimism, being of great relevance for the acceptance and search for meaning in life, the proximity of death⁽¹⁵⁾.

In our study, for the person with chronic oncologic pain, believing and sharing with the transcendent or the divine functions as a source of support and is a way of maintaining hope, not feeling alone and giving meaning to life. In the study carried out by Bonomo et al, it was concluded that the use of spirituality produces, in some way, in the patient's psychological state a greater positivity, compared to those who do not, generating a greater/better way of coping with adverse situations and helping to improve the quality of life⁽¹⁶⁾. In this context Araújo mentions, according to studies, that "patients who accepted to receive spiritual help, who believed in their spirituality or followed the practices of some religion, suffered less from the disease and had an improvement, different from those who did not believe or did not practice it"⁽²⁾. Still in Mesquita et al's study, patients consider spirituality/religion important in their lives and would like health professionals to address this issue by offering spiritual assistance⁽¹⁷⁾. In this way, it is intended that health professionals be attentive "to diagnose and evaluate phenomena related to spirituality"⁽¹⁸⁾, so that they can help and respond to the needs of their patients in the spiritual dimension.

Spirituality can be understood as that which allows us, as human beings, to experience the transcendence of life, that which is beyond us. In another study⁽¹⁹⁾, for the participants, two concepts were emphasized in relation to spirituality: one attributed to religious belief and another to the dimension that transcends the body. We can say that the search for meaning for suffering along with faith - belief in a transcendent higher power, not necessarily God, will be the key elements in the basis of the definition of spirituality. In the person with chronic oncological pain, spirituality acts in the development, orientation and rehabilitation of the person and consequently generates quality of life, by prolonging the expectations of living⁽²⁾. However, we cannot discard religiosity since it "is part of the spirituality of the individual"⁽¹⁹⁾, promotes comfort, hope and "favors confrontation and acceptance of adversities"⁽¹⁹⁾.

In the person with chronic oncologic pain, in parallel with the progression of the disease, the existential issues aggravate, so the spiritual dimension should receive as much attention from the professionals as the clinical approach itself⁽²⁰⁾. However, Nobre adds, "many times the spiritual aspect is forgotten, it being the competence of health professionals to be aware of the spiritual dimension of the patients and it is in the final phase of life that this dimension assumes greater importance"⁽²¹⁾. In this way, the need for preparation and knowledge of health professionals at this level is indisputable. Their inner availability and ability to listen is essential, so that they can understand the hope of the sick person without projecting the patient's own hopes into the patient, so that they can take care of in a holistic and humanized way given, besides so many other aspects,

the spiritual needs of patients⁽¹⁹⁾. This requires those who take care of, among other virtues, the commitment, love, attention and respect⁽²²⁾.

CONCLUSIONS

The person with chronic oncological pain is confronted with the imbalance not only of the physical dimension, but also with the instabilities that arise both in the psychological and social field and in the spiritual dimension, in which it welcomes within itself and effects a work of inner search, of confrontation with itself. It reflects on what he has lived, seeks the meaning of what he has accomplished and experienced, as well as the acceptance of what he did not realize, and thus contributes to his inner growth and enrichment of Being.

At this stage of life, the spiritual dimension is exalted, embodies and becomes a prodigious tool, transmitting hope and inner strength, comfort, faith, better understanding about the meaning of life and ability to discern in the proximity of death. Being that the hope is perceived by the study participants as an inner force that transcends, stimulates and leads to positive thinking. Patients view the present situation as one more step to overcome.

In regard to faith, it is conceived as comfort, as a source of support relating to hope. Faith, too, in establishing a belief in the transcendent or the divine, is based on sharing which enables study participants to reduce anxiety, maintain and restore hope.

Accompanying these patients in hope requires availability and inner closeness as well as listening ability, for relational competence, that is, the art of relating to the sick person, accompanying it in hope and faith, involves the field of "knowing knowledge", that is, theoretical knowledge, training; as well as the field of "know-do", which relates to the techniques of the relationship of help and the field of "knowing how to be", which involves the inner dispositions and attitudes, with the purpose of listening and understanding of hope of the patients, leading them to a new consciousness, to the development of the spiritual dimension and enrichment of the being.

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