

RIASE

REVISTA IBERO-AMERICANA DE SAÚDE E ENVELHECIMENTO
REVISTA IBERO-AMERICANA DE SALUD Y ENVEJECIMIENTO

LEARNING IN THE EXPERIENCE OF THE PERSON WITH ONCOLOGIC PAIN A PHENOMENOLOGIC STUDY

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ABSTRACT

Objective: to understand learning in the experience of the person with chronic pain from the oncological forum.

Method: a qualitative approach, using phenomenology, with ten cancer patients followed in the consultation of pain. As a data collection instrument the partially structured interview and the phenomenological analysis were used. The research was approved by the Ethics Committee of ULSBA, EPE.

Results: from the grouping of meaning units, the central themes emerged as one of the themes: learning in the experience of the person with chronic pain of the oncological forum. From the grouping of the units of signification for this central theme, the subthemes were identified: valuing the Self and learning from the disease.

Conclusion: Some study participants consider that they learned and grew inwardly with the disease situation experienced. They began to value moments lived, strengthened family ties and found new meanings for life.

Keywords: Chronic pain; medical oncology; patient; learning.

INTRODUCTION

This research reproduces a part of the path taken in the scope of the Doctorate Course in Nursing, in which we focus on learning in the experience of the person with chronic pain of the oncological forum. Although man is aware that he is mortal and that death is part of life, it is perceived as a distant event, which happens only to others and not to themselves, and each person attributes a meaning to their death in function of the meaning it gives to your life, it was be said that one dies as one lives. Although man is habitually able to control the vicissitudes that cause him pain, confusion or resentment, it is important to point out that "his freedom consists in deciding what actions to take in the face of a period of pain. Of these options depends their greatness and weakness, because, in the way of experiencing the winter, we can guess the spirit of spring"⁽¹⁾. In the vast majority of cases, in the face of adversity, the sick person tries to resist it, develops revolt, sadness, lets suffering involve it, and it becomes exhausting and destructive. It is imperative that the sick person accept the adversity he or she encounters, accept the suffering, perceive the aspects that are beyond his control, and understand that by maintaining his dignity and courage he can change the way he is and feel in the situation you are experiencing. Thus it is possible to find a meaning in suffering, which can only be the

acceptance that it is part of life, through a constructive attitude that allows one to face it with greater serenity, with better wisdom and to avoid that it is destructive, because "what destroys man is not suffering, it is suffering without meaning"⁽²⁾.

In the person with chronic pain from cancer, suffering can be a factor of readjustment, learning, inner growth and development of the spiritual dimension, enabling new challenges and new meanings for life. In this context, it is essential to accompany and assist the sick person in identifying and discovering new values that arise in the face of their illness situation, for "discovering new values, seeing life as a mystery, living suffering as an occasion to mature, despite it, may be points of light that ... can mark a route to live the situation of proximity of death"⁽³⁾. We can say that the situations of adversity that man experiences throughout his life, from illness, pain, suffering, "need time to become a phase of growth and hope; it is often necessary to accept confusion and disturbance as an intermediate step before reaching a different perspective and inner peace"⁽¹⁾, and a space for reflection is indispensable, together with a work of inner search and confrontation of the person sick to herself.

METHOD

Being the objective of this investigation, to understand the experience of the person with chronic pain of the oncological forum, we opted for a method of qualitative research using phenomenology, once the phenomenological approach allows to study the phenomenon from the meaning that it has for the identifying their perceptions of reality, looking for their individual particularities, their meanings and their experiences. Phenomenologists "try to penetrate into the conceptual world of their subjects, in order to understand how and what the meaning they construct for the events of their daily lives"⁽⁴⁾. It is the descriptions of the person who constitute the data source, through a descriptive analysis of the meanings of the language. This analysis consists of "penetrating the intentional meaning contained in the descriptive data"⁽⁵⁾, in order to discover in them the essence of the experience lived by the person.

From the total number of patients followed in the Day Hospital Service of the Local Health Unit of Baixo Alentejo, a sample of ten patients was selected according to the inclusion criteria defined by the researcher, being the following: having oncological disease; be followed in consulting the pain; have their cognitive ability preserved (data obtained with the Mini Mental State test) and agree 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"⁽⁶⁾. We used the partially structured interview as a data collection instrument, for which we elaborated the interview script, and the proposed themes involved: the description of the pain; to live the day-to-day with the pain; the way of dealing with the limitations imposed by pain/disease and the management strategies used in pain control.

The data collection process was carried out between October and November 2010. The interviews were completely transcribed and stored in a computerized Word format, which was designated by letter (E) followed by a number from one to ten, which corresponds to each of the ten patients who participated in the study, thus ensuring confidentiality. In this way, the ten interviews performed, to the ten participants, constitute the corpus of analysis of this study.

After the interviews and their transcription, we made several readings and re-readings of them and in order to understand the totality of the participants' discourse, besides the verbal message, we used some symbols capable of helping to understand the express non-verbal language because "(...) many times the words are not enough for the patient to express the total pain they are feeling and may not even use them, hence we must be attentive to what the patient transmits us in a non-verbal, to better understand their pain"⁽⁷⁾.

Thus, in the units of signification transcribed, the expression of the gaze of suffering is represented by the symbol () and the expression of the look of hope is denoted by the symbol (--).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 chose to follow the methodological course recommended by Deschamps, which consists of four stages, the first one involves the highlighting of the overall meaning of the text, because through the various readings made from each of the interviews, this stage allowed the researcher to enter in the content of the text and familiarize themselves with the experience reported by study participants. The second phase of the data analysis concerns the identification of units of meaning, in which the text was subdivided into units of natural meaning, that is, the units of meaning were identified through a spontaneous analysis of the researcher, always maintaining the total respect of what was said by the study subjects. In this way, after the grouping of units of meaning by content, the central themes emerged. The third stage of the data analysis refers to the development of the content of the units of signification, in this phase, the researcher deepened the understanding of the units of signification when analyzing the central themes, and these were later decomposed into sub-themes. 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 through the meeting of the units of meaning in depth, made a consistent and coherent description, which took a synthetic form, this last step composed of three distinct operations: a 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.

In order to ensure the validation of the results we returned to the study participants for validation of the descriptions, all of which were validated.

In the field of ethical issues the request for authorization was made to 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 proposed research. 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. All ethical procedures were followed as recommended by the Helsinki Declaration of Ethics in research involving human beings⁽⁸⁾.

RESULTS AND DISCUSSION

During the analysis of the data, through the grouping of units of meaning by content, emerged the central theme: learning in the experience of the person with chronic pain of the cancer forum. In the analysis of the aforementioned central theme, the sub-themes were highlighted: "Valuing the Being" and "Learning with Disease". The identified sub-themes were approached by the subjects of the study with involvement and depth, allowing the researcher to understand that the aspects that make up the mentioned subtopics were for the participants of extreme importance and had a great impact on their lives.

Valuing the Being

It is essential to have a personalized attention of the person with chronic pain of the oncological forum, at the level of the various dimensions, because it is a living person, with a history, with desires, hope, with affective and relational needs, and "having" cease to be important, and only "being" takes on importance and becomes paramount. In this way, in addition to receiving the physical, psychological and social aspects of the sick person, we

must also take care of their spiritual dimension. However, many times the spiritual aspect is forgotten, in the face of adversity and in the final phase of life this dimension assumes greater importance.

The relationship with the proximity of death leads the person with chronic pain of the oncological forum to question the meaning of life and the meaning of death, and it is fundamental to identify their spiritual needs and to accompany them in their journey. Some of the needs in the spiritual field are referred to by Bermejo, one involving "anguish and difficult questions"⁽³⁾ because the patient can question himself, blame himself and feel distressed. In this situation the patient must be listened to, since active listening is fundamental to understand him/her in its entirety. The same author adds, that knowing how to accompany anguish "means above all giving space to the formulation of the cognitive and emotional impact that the proximity of death produces. It is about being open to dialogue and facilitating emotional drainage."⁽³⁾ The "question of meaning and the personal valorization of death"⁽³⁾ is another of the needs of these patients in the spiritual field, pointed out by Bermejo, and it is fundamental here that the patient is assisted in identifying and discovering new values that arise to the situation of illness, such as paying attention to those around him, to value small gestures and attitudes, to live each day, that is, to live the disease situation as an opportunity for maturation and inner growth. Another of the spiritual needs of these patients involves "reconciliation with one's own life"⁽³⁾, in which the patient reflects on their life and takes stock of what they did and did not do. It is often said that "(...) the way of dying depends a little on how one lives, that is, on what one feels he has been able to do in his life: a full and sensible life or an empty and meaningless life."⁽³⁾

In the study carried out by Querido, the participants stated that living day-to-day "means adjusting the experience of the situation every day. The reports suggest that there is an influence of the temporal dimension and the perception of death as the present limit, in the way the participants manage their hopes in order to keep them"⁽⁹⁾. Some subjects in our study also refer to the importance of "being" they are and to live one day at a time:

" (...)Today (...), I live one day at a time, because today I feel good but tomorrow I do not know, I can have a stronger pain that makes me impossible ... (), I may not be able to get up. I prefer to live one day at a time, I'm used to living like this ... (), I stopped having plans, projects (...)." (E3).

"I also failed to give importance to material goods. I do not care to buy for myself, I feel better when I give to others. I started to give more importance to the being that I am and to being with others (...)." (E3).

" (...)I like, I like to smile ... (--), and then on this issue of collaborating with people who suffer ... is one of the good things ... it is not giving money, giving this or that, for me is precisely to help with affection and affection to those who need it (...)." (E9).

Also the study carried out by Carvalho and Merighi, made it possible to understand the subjects of the study "as beings open to transformations, able to reach their own being, to seek their own truth, recovering the meaning of caring in another dimension, (...)." ⁽¹⁰⁾. Still in the same study, the authors verify that the patients, when confronted with the process of finitude, try to appreciate what previously went unnoticed, value, recreate, that is, transform their world, replacing the losses with a new way of living and to be with others. In the same way, the importance of affections and small gestures is perceived in our participants:

" (...)It is important to give, give to others to receive also, give and receive Love." (E3).

" (...)Often it is not the material sense of things, it is almost affection, and sometimes a word, a gesture, represents more than anything material that one can give, because one is in need and often is not, material things, it is more of the affection (...)." (E9).

" (...)It is important to say:

- Look, he remembered me!

Because today there is a lot of selfishness. People are very closed and then affection costs nothing ... (--), and giving people also receives (...)." (E9).

The person's behavior in the face of a fatality, according to Paldron, may oscillate, "between the extremes of total selfishness and the most unexpected altruism. However the basis of consensual understanding is generally the solidarity"⁽¹¹⁾. The same author adds that, faced with a difficult situation, "a spontaneous union of all efforts is born to overcome it. This attitude is natural in the human being, and allows one to transform suffering, giving it an altruistic sense."⁽¹¹⁾. We can say that the capacity for inner growth of the human being, that is, of spiritual transformation and openness, comes mostly from the great adversities of life, so it was with some subjects of our study. For it was the chronic pain situation of the oncological forum that enabled them to look singularly at those around them and to feel useful and willing to help other people by not focusing on themselves.

Learn from the disease

The sick person can develop his spiritual dimension, learning to recognize his internal resources and consequently producing an inner transformation, both in his capacities and level of consciousness, in his behaviors and attitudes. Obstacles, difficulties and adversities in life may not affect the person in such a severe way when they are able to focus more on those around them than on themselves, when they are able to help others and seeks to have altruistic goals. For when a person ceases to be solely centered in himself, his problems become more diluted, they become diminished, because they cease to occupy the whole space of his "being", once it becomes filled with altruistic attitudes, which contributes to your inner growth and gives you the capacity to deal with adversity, to accept suffering and to find meaning. In this way, "we thus prepare the ground to be able to transform and even transcend suffering"⁽¹²⁾. The same author also says that "spiritual training (...) generates a global attitude of goodness and nobility of heart. With goodness and altruism, our life makes sense and the conditions for happiness to meet without effort"⁽¹²⁾. We can thus say that the development of spirituality leads to a transformation, that is, to an inner growth of the person and there is a strengthening of the self. In this perspective, Benito, Barbero and Payás point out that "the sense of belonging to a higher whole and the connection with this source of life gives us internal consistency, motivates us, empowers us, gives us energy and gives us confidence and hope and, she is more capable of facing difficulties and problems"⁽¹³⁾. In this context, we can add that spirituality cannot be taught, it can only be discovered, because the awakening of the spiritual dimension is the fruit of the unique evolution of each person. In situations of existential suffering or questions that arise about the reality in which the suffering person lives, "there is a search aimed at transcending the narrow view that can keep it installed in the suffering, and promotes the acquisition of a deeper vision of itself as part of a higher reality"⁽¹³⁾. The same authors add that spirituality is a personal search movement in three directions:

- Search for the meaning
- Search for connection
- Search for transcendence

In the search for Sense, Benito, Barbero and Payás refer that spirituality "comprises a personal search for meaning, the meaning of life and death, the value of oneself: their acts, their person, their circumstances. It is the need to integrate the various aspects of our life and our being: to recognize, to embrace, to accept our successes and failures (...)"⁽¹³⁾. So says this study participant:

" (...)I acknowledge that I also gave all that I had, I created my sisters just as I raised my children (...). I am happy about it ... I am still a reference today, by the way I created them, (...) I gave them what I could, (...)." (E9).

" (...)Sometimes there are phrases, there are moments, there are so many things ... that, sometimes, we find out that if it were not for that stop, that lack of health that we had, we ended up not knowing that in fact there is the other side ... (--),the good side of the family (...)." (E9).

It is at the same time "to give value to everything that we have been, we have done, we live from honor and generosity, from love; to all that contributed to our happiness and to that of others; to everything that made us grow and mature"⁽¹³⁾. As Hanh tells us, it is about watering the seeds of happiness that we all have within us⁽¹⁴⁾. The subjects of the study continue to consider this importance:

" (...)I also think there are other people who still suffer more than I do, have other major losses, and I turn my thoughts around. It is the life that teaches us, we learn from problems to raise our heads (...)." (E6).

" (...)Those who have lived such a heavy loss, as the death of my daughter, has become more prepared for other strikes, it is as they say: what does not kill us strengthens us." (E10).

In the search for Connection, Benito, Barbero and Payás mention that "spirituality, as a human dimension, also has a facet of openness. It allows the individual ... to recognize himself as an integral part of himself and as an important member of society"⁽¹³⁾. The same authors add that "the person's feeling is of connection, of belonging (belonging) and of responsibility towards himself and towards the others who become closer, closer"⁽¹³⁾. This happens with the participants of our study:

" (...)When I realize and easily perceive someone who has cancer, who walks in treatments, I feel like giving him a smile, saying I know what it is, giving him a word of strength ... (--), that's how I feel." (E3).

" (...)Sometimes it is necessary to go through these things to know that someone loves us, that someone wants us well, because we sometimes, on a daily basis (...) when we deal with people we do not give due attention. I'm in the mood for this to happen to me a little ... (--), to discover that we are indeed loved and do not know (...)." (E9).

" (...)I love, I love family ties, for me they are ... (--),always, I have always preserved them, but now with this situation I have in fact discovered that there are very strong ties (...)." (E9).

The search for Transcendence, according to Benito, Barbero and Payás, is based on the capacity to “expand, (...) having a deeper and wider perspective of our self and our present circumstances, including suffering and death, (...)”⁽¹³⁾. Thus, one of the study subjects reported:

“ (...)I look at things differently, I look at what I did not like before, like the leaves of the trees, the sounds of nature and even people with disabilities (...)” (E3).

They reinforce the same authors that the spiritual dimension involves “a dimension of transcendence: of departure, of openness to another level of non-rational but intuitive consciousness that opens us to new realities and beyond ourselves. (...)”⁽¹³⁾. The capacity for transcendence focuses on the potentiality of the self and understands the existence of an ever present inner force. Adversities, such as sickness and death, are times of spiritual pursuit.

So continue to verbalize our participants:

“In day-to-day life I did not stop, I never had time for myself. Now, in my sickness situation, I have found time for myself, it is a different time, it does not run away as it did before (...)” (E3).

“ (...)Now I have more time, it's a different time, I appreciate things more. When we are new time is not enough, it is a rush, and at this stage of life we have plenty of time, so if we appreciate things in a different way, that's how it is.” (E5).

Remembering Lazure “ (...)we must remember that time is an abstraction. It is not the time that is long: it is we who are bored; it is not time that passes quickly: we are walking faster and faster. (...)Time is neutral, we qualify it, we color it”⁽¹⁵⁾.

In this perspective it is necessary to revive, to brighten up, to offer quality to the time for the person to be with himself and to appreciate the small things that in the day-to-day go unnoticed:

“ (...)I began to give more importance to other things I had not seen before. Let me give you an example: I went to the countryside (...) and started looking at the leaves of the trees, (...) listening to the sounds of nature ... (--), (...)” (E3).

“ (...)I appreciate other things: the trees, now the fall of the leaves begins, the birds, the afternoon when they begin to settle in the branches of the trees, (...) it is like this, but before did not like these things either, (...)” (E5).

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:

" (...)I ask several times:

- Why me? For what?

To the question, "Why me?" I do not know, I cannot find an answer, but when I ask myself, "For what?" I know it is to learn, to learn more, to look at the world in another way, (...)to stop and reflect, (...)." (E3).

" (...)This calming in life gives us more relaxation and I seek this relaxation through the walks I do in the morning (...)." (E9).

For some of the participants, the situation of adversity experienced gave them a space for reflection and, consequently, to appreciate and value the small things that are unobserved daily, that is, the subjects of the study begin to give each thing its value:

" (...)These mishaps on the line of life, in our lives, sometimes awaken us, we are told: there are others, there are more values, there is this, there is that, that is to have a little attention, because life, life, if we live it continuously without stopping, we end up not giving it the right value (...)." (E9).

In this way, we find that some of the subjects of the study relativize their own suffering by not focusing on themselves and giving more attention to what was previously unnoticed, such as small things, from the sounds of nature, the leaves of the trees, the arrival of autumn, and its own autumn. They also become more attentive to gestures, attitudes and human values, expressing openness and compassion for the suffering of those around them, a willingness to help, to smile and to give a word of support to those who are also living a sickness situation oncologic.

In the study by Guerreiro, Zago, Sawada and Pinto it is verified that "cancer still carries the stigma of suffering, anguish, indignation and fear in the face of uncertainties of the future (...)"⁽¹⁶⁾. The same authors add, however, that "such meanings (...) lead these patients to face this fear and thus produce an intrinsic force generated mainly by the will to live and (...) a real meaning to life itself, being able to renew themselves in the face of complex transformations in their existence"⁽¹⁶⁾.

Also in our study, some of the participants show a wide interior availability, a greatness and spiritual openness that allows them to appreciate their surroundings with greater acuity, and to relativize what previously preoccupied and filled them, offering quality to the moments lived. We can say that for some subjects of the study the situation experienced led them to a transformation, to their growth and inner knowledge that enabled them to transcend suffering.

CONCLUSION

We verified in our study that the person with chronic pain of the oncological forum, despite the situation or through it and the changes caused both physically, psychologically, socially and spiritually, can learn from the illness, grow inwardly, develop their spiritual dimension and , consequently transcending suffering. We note that the subjects of the study failed to attach importance to material goods, they exchanged these for a gesture of affection, a smile, or a word of comfort, and they became more attentive to those around them in similar situations of suffering.

Compassion for others, kindness and altruism help the sick person to relativize their adversity and to appreciate, to be more attentive to those around them, as well as to give each thing its value, that is, to value the small things of daily life that previously went unnoticed in the daily routine, from the gestures, the attitudes and the presence of the family. When this happens, life takes on another dimension, it gains another meaning and happiness can be achieved.

Suffering is lived in a unique way by each person, because it constitutes a unique, singular moment of confrontation of the person with himself, which allows him to stop and reflect. In this way, we can say that some of the participants in our study were able to integrate suffering, and this was a factor of readjustment, of internal growth and development of the spiritual dimension, and enabled them to value the moments lived, to strengthen family ties and to find new senses for life.

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