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CHANGES IN DAILY LIFE IN THE EXPERIENCE OF PEOPLE WITH ONCOLOGIC PAIN

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ABSTRACT

Objective: to understand the changes in daily life in the experience of people with oncological pain.

Method: study of qualitative nature and phenomenological method in the data analysis. The study subjects were ten oncological patients, accompanied through the pain consultation. We used the partially structured interview as a data collection instrument, with the guiding question being: which changes occur in the daily life in the experience of people with oncological pain? The research was approved by the ULSBA Ethics Committee, EPE.

Results: from the grouping of significance units the central themes emerged, with one of them being: changes in the daily life in the experience of people with oncological pain. From the grouping of significance units for this central theme the following sub-themes were highlighted: autonomy loss in the performance of domestic tasks and loss of ability to perform the respective professional activity.

Conclusion: people with oncological pain face a loss of ability to perform the tasks they previously performed and are confronted with pain and disease-imposed limitations in their professional activities, which many times lead to an anticipated retirement.

Descriptors: cancer pain; patient; daily life activities.

INTRODUCTION

The chronic pain of the cancer forum does not lie in the simple question of the impulse to travel along a nerve, but in the result of a conflict between a stimulus and the person as a whole, which translates into a whirlwind of emotions, feelings, attitudes and behaviors that mirror, in a unique way, the extent of suffering. Oncological pain when reaching the person encompasses all dimensions, from the physical, psychological, spiritual and social dimensions⁽¹⁾, where the work and family scope is included. Pain and other physical discomforts associated with the pathology lead people with cancer pain to face multiple changes, at various levels, leading them to adaptations that completely transform their life, but also that of those around them. In addition, cancer treatments, in most cases, involve invasive and painful procedures, which lead the sick person to a set of bodily changes that not only alter the body, but also intervene in daily activities and in their identity⁽²⁻⁴⁾. Oncological pain removes the will and causes several losses, as it limits the sick person in their day-to-day actions and makes them dependent on others in carrying out the same, namely their family members. The family being an interpersonal system⁽⁵⁾, whenever one

of the family members is faced with a disease situation, it is felt as a threat to the functioning and satisfaction of the household's needs. Because family members are always involved, in one way or another, according to the dependence of each one on the sick person and the associated obligations. Chronic pain from the oncological forum arouses various feelings in patients and family, disorganizing existing relational models and reconstituting perceptions and forms of behavior within the family⁽²⁻⁶⁾, leading to changes in the distribution of roles within the family and changes in the labor field.

Thus, the guiding question emerged: what are the changes in daily life in the experience of people with chronic pain from oncology? In this sense, the objective of this research is to understand the changes in daily life in the experience of people with cancer pain.

METHOD

One opted for a qualitative research using the phenomenological method from the perspective of Martin Heidegger⁽⁷⁾, since the present study aimed to understand the changes in the daily experience of the person with cancer pain, from the guiding question: what are the changes in the daily experience of the person with chronic cancer pain?

The fundamental issue of Heidegger's philosophy is not man but "Being", "the meaning of Being", as the Heideggerian method makes it possible to understand "Being", through the description of the situations that individuals experience⁽⁷⁾. It is the person's descriptions that constitute the data source, through a descriptive analysis of the meanings of language. This analysis consists of penetrating the intentional meaning contained in the descriptive data⁽⁸⁾, in order to discover in ourselves the essence of the experience lived by the person.

The phenomenological approach makes it possible to study the phenomenon from the meaning it has for the person, looking for their experiences, that is, their meanings, their individual particularities and identifies their perceptions of reality, as phenomenologists seek to enter in the conceptual world of their subjects, to understand how and what the meaning they construct for the events of their daily lives⁽⁹⁾.

A sample of patients followed at the Hospital de Dia Service, at the Local Health Unit of Baixo Alentejo, EPE, was selected. The inclusion criteria were defined by the researcher: having cancer disease; be followed in the consultation of pain; accept to participate in the study and have their cognitive ability preserved (data obtained with the application of the Mini Mental State test), with all subjects of the study having their cognitive abilities

maintained, making a total of thirty points in each test. The selection was made intentionally, because “the logic and the power of the intentional sample is in the selection of cases rich in information to study in depth”^(10:169). The semi-structured interview was the data collection instrument used. We prepared the interview guide, with the proposed themes: the description of the pain; living day-to-day with pain; how to deal with the limitations imposed by pain/illness and the management strategies used to control pain. The study involved ten participants, aged between 44 and 76 years old, six of whom were female.

The data collection process took place between October and November 2010. The interviews were fully transcribed and designated by the letter (E) followed by a number from one to ten, which corresponds to each of the ten study participants, ensuring if so confidentiality. Thus, the ten interviews carried out constitute the corpus of analysis of this study.

Several readings and re-readings of the transcribed interviews were carried out, and with the aim of understanding the totality of the participants' message, in addition to the verbal message, we used some symbols capable of helping in the understanding of the non-verbal language expressed by them, because “(...) many times the words do not reach the person to express the total pain he is feeling and he may not even use them, it is essential that health professionals are attentive to what the person transmits, either verbally or not-verbal, to better understand your pain”^(11:1379). Thus, in the transcribed units of meaning, the expression of the look of suffering is represented by the symbol () and the expression of the look of hope is designated by the symbol (--). The silences in the participants' speeches accompany their expression of the gaze and are identified with the three-point punctuation mark ...

Data analysis followed, where we proceed to the different stages of phenomenological reduction. We chose to follow the methodological path recommended by Deschamps⁽⁸⁾, which involves four stages, the first one highlighting the overall meaning of the text. This stage, through the multiple readings taken from each of the interviews, allowed us to enter the content of the text and familiarize ourselves with the experience reported by the study participants. In the second phase of data analysis, the units of meaning were identified, and the text was subdivided into natural units of meaning, that is, the units of meaning were identified through a spontaneous analysis, always maintaining full respect for what was said by the study subjects. Thus, after grouping the units of meaning by content, the central themes emerged. The development of the content of the units of meaning represents the third stage of data analysis. In this phase, we deepened the understanding of the units of meaning when we made the analysis of the central themes,

and these were later decomposed into subthemes. The fourth and final phase of the analysis of a phenomenological study involves the synthesis of the set of units of meaning. In this phase, by grouping the units of meaning in depth, we made a consistent and coherent description, which took a synthetic form, the last stage being composed 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⁽⁸⁾.

In order to certify the fidelity of the data, the categorization process was brought to the attention of two expert researchers.

Subsequently, we returned to the study participants to validate the descriptions, in order to ensure the validation of the results, all of which were confirmed.

Regarding ethical issues, the authorization request was made to the Director of the Local Health Unit of Baixo Alentejo, EPE where the study took place, as well as the opinion of the Ethics Committee of the Health Unit mentioned above, and we obtained authorization and approval for the performance of the investigation with approval number 196. The Free and Informed Consent Form was signed by all study participants, and it presented the research objectives, as well as the guarantee of anonymity. All ethical procedures were also followed as recommended by the Helsinki Declaration of Ethics in research involving human beings⁽¹²⁾.

RESULTS AND DISCUSSION

During the analysis of the data, from the grouping of units of meaning by content, the central theme emerged: changes in daily life in the experience of people with cancer pain, and from the grouping of units of meaning for the aforementioned central theme, they stood out if the subthemes: "Loss of autonomy in carrying out domestic tasks" and "Loss of ability to perform professional activity". The identified sub-themes were approached by the study subjects with involvement and depth, allowing us to understand that the aspects that make up the sub-themes mentioned were of enormous importance for the participants, and had a great impact on their lives.

Loss of autonomy in carrying out domestic tasks

Chronic diseases or serious adversities, such as chronic cancer pain, can irrevocably condition the person's ability to perform daily activities, since the disease itself can alter the identity of each person⁽¹³⁾, modifying your ability to perform tasks that you previously performed autonomously. The oncological disease, being chronic and debilitating, associated with pain, and leading the sick person to the loss of his ability to perform daily activities, transports the patient to dependence on others, namely his family. Thus, when the disease arises within the family, it implies several adjustments in its habits, as well as the adaptation of its elements to the new situation:

"(...) For example, I can't get clothes out, but my husband there helps me (...)." (E6).

"At the beginning of the disease, I didn't do anything, I didn't feel like doing anything, nor did the pain stop, (...). The pain wouldn't let me do anything, nothing, (...), my daughter had to do everything (...)." (E7).

"(...) The thing that costs me the most is washing the floor or sweeping because there is a lot of effort, there is a huge force on the arm, it is usually the daughter or husband who do these things." (E10).

The disease causes a set of changes and changes both in family routines, rules and rituals, in the redistribution of roles and in the addition of new responsibilities and competencies⁽¹⁴⁾.

In the study carried out by González-Rendón, and Moreno-Monsiváis, it appears that the daily activities of life with limitations, from moderate to severe, due to pain, involve "driving or using some type of transport (54.3%), sleep (51%) and, above all, housework (67.6%) and walking (62.92%)^(15:8), just like in our study:

"I was doing my housework. I did my shopping. I did all my things, from my house, now I can't ... (), (...)." (E1).

"(...) Painting a house, that is no longer the case, I am no longer able to do these things. Not rubbing a carpet either, and now, since the catheter was placed for chemotherapy, even less, because it limits my movements, (...)." (E4).

Patients find it difficult to carry out activities that they previously carried out effortlessly, and today they are faced with the fact that they are unable to accomplish the smallest daily tasks, due to pain:

"(...) I have days that even just buying bread and anything else, which I used to bring easily, now I come home even very tired, with pains that also extend to my back and shoulders, and I have no strength at all (...)." (E4).

"It costs me a lot to iron because of the heat of the iron, because of the catheter, today I iron a little outfit, tomorrow I iron another (...)." (E6).

The person with cancer pain undergoes a change not only in their physical dimension, but also in the psychological, social and spiritual dimensions because "the disease causes a rupture in the life of the human being and its future existence will correspond to the search for a new balance. (...) In chronic pain, it is no longer a localized disease that we talk about, but an entire organism that suffers and adapts"^(16:148). Adapting to the new situation often leads patients to revolt:

"There are certain things that the person is going to do and is not able to. (...) For my age it is a bit complicated... (), I am 46 years old and there are certain things that cost me a lot to do, because I have limited shoulder movements. Just yesterday, for example, I wanted to button my apron and I was not able to, these are the little things that sometimes cost and then there is the person... () feels a little bit of revolt (...)." (E4).

"(...) I am very revolted ... (), because I am a person who has always been working. I left my job, came home and could be up to midnight doing everything and anything, from home. When this happened to me it was like a bucket of cold water, because I was unable to do my things ... (), I was a person who did everything and I had to stop doing it, due to the pains (...)." (E6).

The presence of pain changes the daily life of the sick person, his relationships with others and ends up breaking his relationship with the world, removing the patient from the desire to perform day-to-day tasks, as the participants continue to say:

"(...) At home I used to do some DIY that I can no longer do..., I don't cook or do the dishes either... (), (...), I get tired and lost my will." (E2).

"(...) I cannot make efforts, (...). Before I did mechanical work at home, I always had my bench where I did some work, now I lack strength in my arms and even willpower. Everything is different... (), what I was doing I can't do today (...)." (E5).

It is verified through the analyzed results of the study that the degree of physical impairment causes revolt, sadness and leads, many times, to the loss of will of the sick person to carry out the daily chores.

Pain and fatigue are two of the most common physical problems experienced by cancer patients. In the study by Rietman et al⁽¹⁷⁾, concluded that pain is the most common disorder after breast cancer treatment, being strongly related to physical disability. This is how the participants of our study refer, who underwent mastectomy:

"(...) When we feel limited in housework, which was always what I did, (...), when the pain does not allow me to make a greater effort, it is very bad... (), I have already been crying, (...)." (E4).

"(...) The thing that costs me the most is washing the floor or sweeping because there is a lot of effort, a huge force on the arm, (...)." (E10).

Referring to the National Cancer Institute in the United States, Battaglini et al, refer that "72% to 95% of cancer patients undergoing treatment have increased levels of fatigue resulting in a significant decrease in functional capacity, leading to a loss in quality of life"^(18:99). In this context, we can add that the person with cancer pain when presenting a reduced functional capacity, makes a greater effort to perform the activities of day-to-day and, in this way, can feel increased tiredness even when the activities they perform require an effort minor physique:

"(...) I can't walk on the street ..., (...). I can't shop, I can't clean my house, (...). I don't have the strength for that ... (), I don't feel the strength, (...)." (E1).

"(...) It costs me a lot to hang up and go shopping. (...)." (E4).

The reduced physical capacity of these patients worsens the fatigue when carrying out daily tasks. Still Battaglini et al add that the impact of fatigue is significant in these patients, leading them to physical, emotional and social limitations⁽¹⁸⁾. Thus, they continue to refer the study subjects:

"(...) I find myself very upset, sad, wanting to do my thing and can't. (...)." (E1).

"(...) I stopped doing the homework, I stopped making the food, the beds ... (), everything, I stopped doing everything. (...). I feel sad for my situation, because I am still very young ... (), I am 44 years old and it saddens me to think about what I was able to do and now I find myself unable to do practically anything." (E7).

Many of the day-to-day activities are described as being as much or more difficult, as the simple activity of preparing meals, as explained by one of the study participants:

"I do a little something, I come to the sofa and lie down for a while, I rest there for half an hour, there I go again to do something else, for example, lunch: I put things on the fire, more or less mark the time and I go to the couch. Then, there I will see how it is, until it's over, and walk this way, with the support of a cane (...)." (E1).

The person with cancer pain is no longer able to perform the tasks he previously performed and feels that his ability to play the roles within the family is diminished. Many of the daily activities are described by the participants as being very difficult to accomplish, due to the limitations that pain and the disease itself impose.

Loss of ability to perform professional activity

In people with cancer pain, the pain lasts over time and adds to the disabilities that arise at a physical, psychological, social and spiritual level, which conditions losses at various levels, from the loss of roles within the family, to losses social, economic and labor⁽¹¹⁾, so say the study participants:

"(...) I cannot make certain efforts, I cannot ... (), I stopped working. I was a bricklayer servant, now it's impossible, I left my job (...)." (E2).

"The job... I had to leave, because I was doing housework at someone else's house and it is a bit complicated. It seems not, but it has to be a lot of force. Now they even reformed me (...)." (E4).

"I worked with my husband in the field, never again... (), I stopped doing almost everything I used to do before, because I can't really strain my arm, I really can't ... (), (...). I will try to address the roles for the reform (...)." (E10).

The job losses that occur in people with cancer pain often lead them to early retirement, leading to economic losses with repercussions for the whole family. The impact is dependent on the role that the sick person plays in the family and their obligations to their families. On the other hand, job losses also have an impact on the loss of status linked to the performance of a socially recognized activity, on the reduction of personal and professional fulfillment, and on social isolation:

"(...) I have always worked with patients, many with cancer, I was a medical aid (...). Having to stop working, leaving home (...), leaving the usual routines (...), it was very expensive... (), because I felt useless (...)." (E3).

"The pain, the disease brought me many changes in my daily life. I was a very active woman and now I am stopped, stopped, stopped ... (), this brought me down a lot ... (), the pain, the disease. I did housework at someone else's house and now I can't (...)." (E7).

"I have a store (...), things are there, they are looking at me saying that they need to be done, and I do not move them (...). I'm looking at that and I say:

- I have to wait for the strength to come for this, ... () because until I gain strength I will not touch anything (...)." (E8).

The person with cancer pain in addition to the pain, the disease itself and the side effects of the treatments, has uncertainties regarding the future, suffering, physical pain, anxiety, depression, loss of control and autonomy⁽¹⁹⁾. Pain can have serious adverse effects on the physical, psychological, social and spiritual status of patients, which is reflected in the activities of daily living and conditions economic, labor and social losses⁽¹¹⁻¹⁵⁾.

Study limitations

This research allowed us to know the limitations and losses faced by people with chronic pain from cancer, in the various dimensions. However, we point out as limitations of this study the fact that the data presented cannot be generalized, since they are related to the specific experiences of the participants. Thus, more research is needed to increase knowledge on the subject studied, so that health professionals are knowledgeable and understand the changes that occur in daily life, in people with chronic pain from cancer.

Practical implications

This investigation certainly contributes to the improvement of scientific knowledge in Nursing, as it led us to reflection and, in this specific case, allowed us to know and understand the importance of being attentive to the daily changes that the person with cancer pain experiences.

Reflection being the basis of our personal and professional growth, it is important to say that this ability makes it possible, both for Nurses and for Nursing professors, to envision personalized care for people with chronic pain from cancer.

CONCLUSION

The person with cancer pain is confronted with their functional disability due to the disease itself and the pain that is inherent to it. However, the present limitations and the losses that are faced, not only reach the physical dimension, they also involve the psychological, social, spiritual dimension, as well as the labor, economic and, consequently, the family field. In our study we found that in the experience of the person with cancer pain, there are changes in their daily lives, namely difficulties in carrying out domestic tasks and loss of ability to perform professional activities.

As for the difficulties in carrying out household tasks, the person with cancer pain is faced with the lack of ability to perform the tasks that he previously performed, and the family adopts this role, that is, the family assumes the patient's role in activities that he

failed to perform, which causes the sick person a feeling of helplessness, incapacity, sadness and even a diminished role in the family. We can say that the impact of the disease on the family causes changes in their daily lives, which leads to the reorganization of tasks within the family. This adjustment to a new living condition has implications and new responsibilities for the family, which will have to organize itself in order to be able to respond to the demands.

Regarding the loss of ability to perform professional activity, it appears that the person with cancer pain is confronted with the limits that pain and the disease itself impose on their professional activity, which often leads them anticipating retirement and other losses, from monetary, social and personal and professional fulfillment.

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