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RESEARCH

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Manifestações e necessidades referentes ao processo de morte e morrer: perspectiva da pessoa com câncer

Demonstrations and necessities on the death and dying process: perspective of the person with cancer

Manifestaciones y necesidades referentes al proceso de muerte y morir: perspectiva de la persona con cáncer

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ABSTRACT

Objective: To know the manifestations and needs concerning the process of death and dying of the person with cancer at the end of their lives. **Methods:** This paper is a qualitative and descriptive case study. The scenario was the participants' homes, who were also bound to the Interdisciplinary Homecare Program, in Pelotas/RS. Five persons with cancer at the end of their lives participated, four were male and one female. Data collection was carried out through semi-structured interviews and participant observation, from August to September 2015. Three or four meetings happened in their homes and thematic analysis was applied. **Results:** Four categories emerged: Emotional demonstrations and necessities; Social demonstrations and necessities; Physical demonstrations and necessities; Spiritual demonstrations and necessities. **Conclusion:** Cancer modifies patients and relatives' lives, which demands skill and sensitive look from health professionals, when aiming to completely assist patients, considering their physical, emotional, social and spiritual dimensions.

Descriptors: Terminally Ill, Palliative Care, Home Care Services, Nursing, Nursing Care.

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RESUMO

Objetivo: Conhecer manifestações e necessidades referentes ao processo de morte e morrer da pessoa com câncer no final de vida. **Métodos:** Estudo de caso, qualitativo, descritivo. O cenário foi no domicílio dos participantes vinculados ao Programa de Internação Domiciliar Interdisciplinar, em Pelotas/RS. Participaram cinco pessoas com câncer no final de vida, quatro do sexo masculino e uma do sexo feminino. A coleta de dados ocorreu por meio de entrevista semiestruturada e observação participante, em agosto e setembro de 2015, com três ou quatro encontros em seus domicílios. Foi aplicada a Análise Temática. **Resultados:** Emergiram quatro categorias: Manifestações e Necessidades Emocionais; Manifestações e Necessidades Sociais; Manifestações e Necessidades. Físicas; Manifestações e Necessidades Espirituais. **Conclusão:** O câncer modifica a vida dos pacientes e familiares exigindo dos profissionais de saúde habilidade e olhar sensível para o atendimento de sua integralidade, considerando suas dimensões físicas, emocionais, sociais e espirituais.

Descritores: Paciente Terminal, Cuidados Paliativos, Serviços de Assistência Domiciliar, Enfermagem, Cuidados de Enfermagem.

RESUMEN

Objetivo: Conocer manifestaciones y necesidades referentes al proceso de muerte y morir de la persona con cáncer en el final de vida. **Métodos:** Estudio de caso, cualitativo y descriptivo. El paisaje fue en las casas de los participantes vinculados al Programa de Internación Domiciliaria Interdisciplinar, en Pelotas/RS. Participaron cinco personas con cáncer en el final de vida, cuatro hombres y una mujer. La recolecta de datos ocurrió por medio de entrevista semiestructurada y observación participante, en agosto y septiembre de 2015, con tres o cuatro encuentros en sus domicilios. Fue aplicado el análisis temático. **Resultados:** Cuatro categorías emergieran: Manifestaciones y necesidades emocionales; Manifestaciones y necesidades sociales; Manifestaciones y necesidades físicas; Manifestaciones y necesidades espirituales. **Conclusión:** El cáncer modifica la vida de los pacientes y familiares, exigiendo de los profesionales de salud habilidades y mirar sensible para atenderlos en su integralidad, considerando sus dimensiones físicas, emocionales, sociales y espirituales.

Descriptores: Enfermo Terminal, Cuidados Paliativos, Servicios de Atención de Salud a Domicilio, Enfermería, Atención de Enfermería.

INTRODUCTION

Death, from the legal medical point of view, is the end of an organism's vital activities, which refers to the irreversible cessation of all brain activity. For Western culture, the concept of death is summed up as an end, as if there were the loss of everything that pertained to life, the total breaking of parental bonds and friendship.[1] The patient, faced with the progression of the disease and with the end of the possibilities of curative treatment, has no possibility of reversion of his health conditions. Referring him to death, he is classified as terminal patient.[2] Faced with this situation, it is thought that nothing else can be done for him, when there is much to do.[3] The health professional, with the prospect that something can be done by the patient in this situation, needs to keep in mind the knowledge produced by the two great personalities in the art of end-of-life care: Kübler-Ross on the process of death and Cicely Saunders with the vision of palliative care and the concept of total pain, which reaches the physical, psychic, social and spiritual dimensions of the human person.[4]

Kubler-Ross has identified the stages through which people pass when they are at the end of life, as follows: Denial (the patient is suspicious of the exchange of exams or competence of the health team, which may be a temporary defense or, in some cases, Sustain yourself to the end); Anger (phase that feelings of anger, revolt, and resentment arise); Bargaining (at a time when the patient makes promises for a prolongation of life or a few days without pain or physical ills, such bargains being most often done with God, may be psychologically associated with a hidden guilt); Depression (referring to the difficulties of prolonged treatment and hospitalization, which increase sadness coupled with other feelings); Acceptance (related to the stage in which the patient begins to accept his situation and his destiny).[5]

Palliative care is aimed at any type of serious illness, simultaneously with curative or restorative therapies that prolong life, and aims to see the patient as a whole, providing him and his family with a better quality of life, involving specific attention, contributing to the control of all the presented symptoms and relief of the suffering, considering the lived experiences and the current situation of this one.[4] However, in this care process, in addition to patients, family and friends are involved, requiring special attention from professionals, an open, clear and sensitive communication practice with all those involved in this context.[6]

A study carried out through an integrative review made evident the unpreparedness of health professionals in dealing with death since graduation. The training courses attach little importance to the approach on terminality, becoming a matter of concern since the health professional's encounter with death becomes inevitable in the work environment.[7] Another study[8] points out that, coupled with the professional's unpreparedness in developing this kind of care, there may be internal difficulties that limit the ability to express feelings about terminal patients and also to listen to them. Such difficulties are understood as a defensive attitude.

There are studies that address the process of death and dying,[5] some indicate the perspective of the nurse[7,9] and others of the caregiver.[3,10] However, besides the author Kübler-Ross,[5] No further study was found that accompanies the patient in this process. Thus, the guiding question of the study was: What manifestations and needs regarding the process of death and dying of the person with cancer at the end of life? From this, this study aims to know the manifestations and needs regarding the process of death and dying of the person with cancer at the end of life**.**

METHODS

This is a case study research that takes a qualitative approach. The research scenario was at the participants' home, which was linked to the Interdisciplinary Home Hospitalization Program (PIDI), in the city of Pelotas/RS, Brazil. This program was founded in the Hospital-School of the Federal University of Pelotas (UFPel), being this one of the pioneers in home care in Brazil.

Five patients with stage IV cancer, who still had the cognitive capacity preserved, were invited to participate in the study, linked to the PIDI, residents in the city of Pelotas/RS, being over 18 years of age. As an exclusion criterion were patients with partial or total loss of consciousness and who were on the waiting list for inclusion in the PIDI.

Data were collected through a semi-structured interview and participant observation, which occurred in August and September 2015. The participants were accessed through home visits with the PIDI team and the access order was established by the earliest date of admission. The meetings were scheduled according to the availability of the participant and the participant observation occurred in all the meetings, with an average of 60 minutes in each meeting and with each participant, being recorded in a file in the program Microsoft Word 2013. The interview of four participants was recorded, according to permission, and one recorded only in a file of the program Microsoft Word 2013, due to the use of tracheostomy, which made the patient's speech impossible.

In this research, after transcribing the interviews, the thematic analysis of Minayo was performed, which is attributed in discovering the nuclei of meaning that establishes a communication, whose presence means something to the analytic object targeted. For the analysis of meanings, the presence of certain themes demonstrates structures of relevance, reference values and behavior models underlying or present in the discourse.[11]

Regarding ethical precepts, Resolution 466/2012 of December 12, 2012, of the National Health Council of the Ministry of Health was respected.[12] The project was referred to the Ethics and Research Committee (CEP) of the Federal University of Pelotas and Received approval under number 1,181,795. In addition, the participant was read and given the Term of Free and Informed Consent and the confidentiality of the participants of the research was preserved through codes to identify the lines, in order to maintain their privacy.

RESULTS AND DISCUSSION

In the study, five patients were interviewed and observed, four are male and one female, and three of these participants have children and two do not. As for caregivers, three are cared for only by the spouse, one by his two aunts, and the other by the spouse also by the children and daughter-in-law. The average age range is 55 years. As for the Civil Status, three are married, one is divorced - having a companion, and the other is single.

From the data analysis, four categories were constituted, which were denominated: Manifestations and emotional needs; Manifestations and social needs; Manifestations and Physical Needs; Manifestations and Spiritual Needs.

Manifestations and emotional needs

In the context of terminality, patients reveal several types of emotional manifestations when questioned about the disease process. Among these, sadness is pointed out.

> *"There are days I get more tired. These days I lay down and cried and then [my wife] saw and was upset. Sporadically I feel sad, but this is normal of the disease itself, getting a little annoyed as it is, if you look in the mirror and you are thin, when you lose your hair. The first time I was very bald, my hair began to fall, I had to shave."* (P2)

> *"I faced positively but sadly because I lost a lot of weight [at this point showed the leg, meaning that I had emaciated]. After the surgery I was even sadder because I stopped talking because of the tracheostomy and did not even taste the food, so I wonder: how does a person have cancer?"* (P3)

At the time of the interview it was observed that all the participants of the research demonstrated sadness in the gaze while talking about their physical limitations, consequent of the symptoms of the disease. Thus, one understands how much these limitations influence the life of the patients, modifying the whole routine, what contributes to enter the phase of the depression, since dreams are interrupted and feelings of sadness appear before these changes.

Sadness is related to the changes of the body, which generate certain limitations. In most cases, they lose their independence, suffer from changes in their body image, isolate themselves from their social bonds, move away from leisure activities and, as a consequence, have a sense of worthlessness.[13] Thus, emotional reactions are generated by various types of feelings, among them the feelings of fear, sadness, anxiety and depression, as much by the illness, as by the direction of difficulty that leads.[14]

Identified needs, such as self-image sadness and the patient's physical problems, may be related to the fear of disability and physical deterioration and the pain of being alone at the time of death.

Fear, especially related to death, was also pointed out:

> *"I want to do the surgery a lot, even if I'm at risk of life, I'm not afraid of death, why stay like this? [Pointed to the belly]."* (P1)

> *"When I went to do surgery in Porto Alegre, I was afraid not to go back and see them (family), that was the part that I was most afraid of."* (P2)

> *"Yes, we always feel fear of death as it is said, a strong thing feels, is complicated, but we can not give up, have to fight to the end, have to go to the end, do everything right. I did chemotherapy, I had surgery and now I'm going to do it all over again, so we're afraid, we're thinking."* (P4)

In the reports of the three patients it is noticed that P1 says that he is not afraid of death even if he does not survive the surgery. Possibly because he can no longer cope with the limitations of the disease due to the negation that has related to it. It was possible to perceive that this patient, when mentioning the above speech, increased the tone of the voice, as if he were angry to know that he has no indication for a new surgery due to the risk of life mentioned by the medical surgeon at another time. P2 and P4 admitted their fears to death, and P2 refers to the fear of dying to their concerns with the family and believing that they will not be well protected after their death. Already P4, even with this fear, decides to do everything possible to continue living, which is, doing everything so that death does not happen. However, she was concerned and sad-looking in thinking and talking about death.

The word cancer is most often linked to the proximity of death.[15] Thus, fear arises in the face of this, making it evident that human beings today are not ready to face their end (when we perceive the denial and shortening of death rites).[16]

Death is an event that occurs for all. However, a threatening illness can make it seem closer, triggering fear along with the feeling of loss for everything one has, such as family, lack of perspective on dreams that have not yet been realized. On the other hand, something makes you think that when these people go through a diagnosis such as cancer, they rethink how they lived their lives before the illness, their mistakes, the correct answers, all these issues are rethought.

During the manifestations about communicating the diagnosis of the disease, the patients also demonstrated the feelings of revolt/anger, which are described in the statements below:

> *"My feeling was of impotence, it was that I thought I was already finished for me already, there my time is over already, what I have here on earth [raised the tone of voice] [...]. The only solution for me is death, that's it [his voice increased again] [...]. I have a little revolt, but it is not a revolt of anger of anybody, it is of the disease."* (P1)

> *"May God help me, after November, I can get off this probe here, which bothers me, that there are times I feel like pulling it out [...]. There is a phase of chemotherapy that we feel thinks of fighting, I do not know if there is a revolt, you dream of a fight, you get angry."* (P2)

According to the reports it is possible to identify that the patients seem to have transited between the phase of depression and rabies. The P1 altered the tone of the voice and the sense of the speech, besides the observation also showed a sad look while speaking. After the interview, he reported that besides the doctor not wanting to serve him, he still indicated the hyperbaric, which left his lesion of that size. Thus, it can be inferred that he feels anger from the doctor and from the disease for having taken the proportion he took, i.e. increased the lesion significantly after the indicated procedure. It was possible to see when his wife showed the photos of the evolution. While he was doing the treatment sessions he presented sadness in his gaze, as well as showing his discomfort at not being able to do his physical activities for the physical symptoms.

In the case of P1, denial and anger prevent him from going deeper into depression, making it clear that the anger/anger he felt was not anger at anyone but illness. In the case of P2, in front of the lines, there is the desire to drop everything or even the desire to escape from the situation.

Depression occurs when the terminally ill patient is no longer able to deny his or her illness, requiring further surgery or hospitalization, when new symptoms begin to appear and make them more debilitated, so they can no longer hide the illness, leading to a feeling of great loss.[5]

The patient in the phase of anger or anger, resentment, envy is often not understood by the people around him, mainly for expressing these feelings, and this can trigger a series of problems with the good relationship between caregivers, professionals and patient. However, it is crucial that family members and professionals do not take the guilt of this feeling generated by the patient, since the feeling of anger is due to illness and the condition that this patient is going through, which is a way of facing it.

The patient needs to be respected and understood, giving him the attention and time to recover from this great scare, being able to recover, promoting the balance of the situation in which he is.[5] Before the analysis, perception and literature is clear that the patient needs much of the understanding of the health professional that serves him, so that his needs can be identified and can be met or, as in the case of these feelings, this Suffering.

Concerns also took on proportions in view of the manifestations evidenced in the speeches, besides being related to the feeling of guilt that the patients demonstrate by facing the process of the disease, to depend on caregivers, as can be seen in the statements below:

> *"And I worry about what my wife is going through, the work she is going through because of me [she lowered her voice, was moved and showed sadness at that moment]."* (P1)

> *"What worries me the most is not the liver disease, the cancer, this is it [fistula], which does not close, if this were to close once and for all, I had it well, I do not think I would worry about liver disease that much [...] I only want to try to improve, close this fistula [...] I want to go to my house, I do not want to get in the way, my aunt likes to go out and she has to stay here with me [she cried a lot] [...]. I wanted to help more [...]. Do not depend so much on people. If it was somewhere else [the fistula in the gut] I think I could even do the dressing myself."* (P5)

In the above statements it was possible to identify that the participants demonstrate to feel guilty due to the change of their routine and consequently of their caregivers, by the dependence of the care that they need due to the disease. With this, it is possible to perceive that more feelings are involved besides the guilt, as the sadness, impotence, feelings that contribute to that these patients are in the phase of the depression.

During the interview and participant observation, P5 proved to be a closed person, who has difficulties in talking about himself, his feelings, besides himself and his aunt having confirmed it after the interview. When these questions were addressed, the patient would respond with sullen eyes, and when we arrived in the middle of the interview he began to sob, sobbing in front of one of his aunts (caretakers). The patient was feeling guilty about depending on the aunts, feeling a burden on their lives. However, her aunt came over and caressed him, making him feel better. In addition, the space provided for such urges to be expressed resulted in patient relief.

Guilt is considered one of the most painful feelings when related to death.[5] Resources used as listening can give time and voice to patients and their families, making them feel more supported and understood. Thus, the concern of this professional is to facilitate communication among all those involved in this process, since it is favorable for the quality of death of a terminal patient to understand their own feelings about dying, in addition to approaching them with relationships with which he wishes to approach.[3]

The professional, acting as mediator between the family and the patient, can guide them and help them in reorganizing their lives. In spite of his closeness to death, he can contribute to the remission of forgotten bonds by forgiving and asking for forgiveness, as well as allowing him to review people who are important to him, seeking to free them from negative feelings, contributing to liberation both for those who are going to leave as for those who will be.[17]

In this context, it is understood that providing spaces for patients so that they can talk about their anguish or fears, feelings and confrontations, enables health professionals to identify the needs of these patients, in addition to contributing to the solutions being sought from this opportunity of listening.

In the demonstrations also appeared the feelings of love and affection when the patients spoke of the most important people in their lives, since at this moment we made sure that their caregivers were present to listen to them.

> *"Oh, I love her [wife], she's part of my life [...] she's an angel."* (P1)

> *"We are very friendly, family, with children, we are very united [...] It was the best thing that God put in my life [wife]."* (P2)

> *"My husband, children, grandchildren and my mother [...] He [husband] is a wonderful person, my children also [...] I have been very surprised with him [husband] because he has Been tireless, tireless even, he runs there, runs here ... I love them with passion [...] Health professionals, I feel so much love for them, affection, gratitude."* (P4)

In such statements the emotion of this moment was observed for all those involved in this work process (interviewers, patients and family / caregivers). In the case of P1, P2 and P4 are all very united, besides having at that moment shown great affection when talking about their feelings for these people, be they wife, children, aunts and health professionals as in the case of P4. In the case of P1, it was observed that the wife was always very present in his life, treating him with affection. The couple shows reciprocity in their feelings. Another example of very rich affection was the case of P2, when the first thing his wife and son with autism do upon arriving home is to greet the patient, kissing and hugging him, showing a lot of affection. Throughout the time of observation, it was evident how much they like to be together.

In the case of P4, the husband arrived and sat down in a chair in front of her, and as she spoke of him and his family, she took both her husband's hands and looked at her with tears in her eyes. During all the time she praised them (husband, children and grandchildren), showing great affection. At all times, the patient and her family shared the environment with much love and affection.

It is of great importance that the professional creates communication strategies useful for care in the face of the end of the patient's life. In the face of worry, he needs to be heard so that his need can be identified, which can be the rescue of relationships, thanksgiving and demonstration of love and affection for the people who are important to him, forgive and be forgiven, say goodbye. But for this, the health professional must be alert to stimulate, allow and promote reunions, to talk with family members, to make visiting hours more flexible, as well as to promote a pleasant environment for these family interactions (providing chairs, a private environment).[18]

Giving this moment to the patient becomes of extreme importance, since the problems with the disease intensify and move very much with the life of all, besides the patient happens to see the death more closely, and this is a form of them Have the opportunity to talk about their feelings to the people considered most important in their life, thus being able to be even saying farewell to their loved ones.

Given the interviewees' approach to their wishes/desires, it was possible to understand that the feelings of hope are linked to the following reports:

> *"Today I want to live, [...] stay with my family, dedicate myself more to them [...] Greater desire is to live, to go without the symptoms, without medicines, and to see them [family] well [...]. If you do not have any perspective on life, something to grasp, it does not go far [...]."* (P2)

> *"I'll tell you, honestly, sometimes I have hope, come time that I drop, feelings high and low, is not feeling 100%. I am trying, praying a lot, clinging to God, trying to get in tune, not letting up, but it is time that I see that my situation is not easy, it is a difficult situation and it is serious, so I am aware of it [...] I wish to stay here with my family, with my friends."* (P4)

From the analysis of the reports of all the patients, they seem to be transitioning in the phase of bargaining and that their wishes/desires are linked to the hope of living. Participants send their will to get rid of physical ills, wishing for the end of drug treatment, making clear the need for a perspective and a sense of life. Given this, what keeps them alive is hope, and this will certainly depend on how they are going to face the disease, this being related to the support of family members, friends, health professionals and the faith that they have or do not have in this process.

At the bargaining stage, the patient tries to postpone his own death by making deals with God, family, and doctors through promises to be a better person if the days of his life are prolonged.[5]

Hope is what motivates the human being to move forward. This feeling can influence people's perception of their quality of life, as well as psychological, physical and social health, and can positively modify their view of the disease. Given this view, it is true that this feeling triggers a beneficial effect on the health of people with neoplasias, simply by strengthening the ability of these patients to deal with crises. However, hope can be understood as a subjective probability of good results, giving meaning to the daily life of people who experience life-threatening illnesses, which contributes to well-being, satisfaction and adaptation to stress factors Caused by illness.[19]

Hope is what usually persists at all stages, and it is what sustains patients psychologically throughout the time from illness to death. It gives the feeling that everything must have some sense, which it can compensate, if they support for some more time. It is also capable of giving terminally ill patients a special sense of mission, which helps them lift their spirits and endure further examinations, surgeries and when everything becomes difficult. For others, it remains a form of temporary but necessary denial. However, it is important that the professional does not give up on any patient, whether or not in the terminal phase. Giving up can contribute to his surrender, which favors meeting with death more quickly. On the other hand, the non-withdrawal of him may cause him to have traces of hope, in addition to continuing to see in this health professional a friend who will be by his side until the end. This attitude can help the patient not to feel lonely, abandoned and so little despised when the doctor considers it out of any possibility of cure.[8]

Manifestations and social needs

The changes in the patient's life after the illness affect their social context, causing changes in their routines, according to the statements below:

> *"I stopped working, I missed working [...] I missed going out with the children. We bought a van just to travel, to leave; we would go to Santa Maria, have the children there, relatives, friends, or I would go to Porto Alegre to do the treatment. These things we do not do, now it's worse because of these chemotherapies."* (P2)

> *"It was the life of a normal housewife, she was going out, she was in the center. It's good that we have a normal housewife life, now with the disease I can not do things, I miss it."* (P4)

Analyzing the speeches, it is evident that the routine with the appearance of the disease completely changed the life of the patients. Thus, these patients with their frailties caused by the disease can be led to 'social exclusion' because of the physical difficulties they are in because they do not have much opportunity to relate to people because they live in function of the disease.

In addition to missing work, P2 misses traveling with her family. With the disease it became clear that changes in his routine also affect his family members, which contributes to a feeling of guilt and sadness on the part of the patient. Already P4 feels the difficulties in establishing his routine work of housewife and of going in the center to walk, things that seem so simple, that are made daily by the healthy people but, because of the limitations, causes great difficulty to put into practice. Due to the degree of impairment of the disease itself, experiencing this disease process can mean deprivation of sociability daily, that is, it completely interrupts the normal course of life of patients and their families. Thus, the fragility imposed by the disease can cause 'social exclusion' because they have to confront a society excluding the most vulnerable.20 Faced with this, social death can happen well before the patient dies, for the abandonment and isolation that he feels in the environment Social, making his solitude prevail, and death being his release from this suffering.[21]

According to the analysis and the literature, it can be inferred that the exclusion of the patient from social life causes great suffering, both for him and for his family. In addition, there is pain, the result of the inability to perform routine activities, which also serves as a reason to cause social death. Many changes happen in the lives of these people, many of whom compromise stability and family routine. Things that seem too simple to do are difficult tasks.

Patients expressed feelings of regret in the face of their lives, such as not having stayed with the family any longer.

> *"That I should have fought more, even to get the things I wanted, to work, to do something different, not just stay at home taking care of the home. I regret not having continued with my studies, of not having done the things I wanted to do, of not having battled more for it and that is something that depended on me. I could have helped more people; I could have done volunteer work. It is that today with this disease we see that how good it is to help our neighbor, you see people helping you, then you say like this: bah could have done it, all his life and not. These days I was sitting here thinking about it."* (P4)

It is noted that P4 regrets not having accomplished socially related things in his life. Perhaps because he was from home, he had the opportunity to live with his family, worrying more about his (social) professional accomplishment.

The patient, before approaching death, gives more value to his life, and it is common to have this reaction, once the disease threatens it. Therefore, one notices the preciousness of each day experienced by these patients, each moment has another dimension: some are attached to the fact that they do not want to leave their children, others enjoy simply waking up, having the opportunity to stay alive for another day, and with that the possibility of the development of actions of its routine. It highlights the sense of appreciation for every minute of life you have left, showing gratitude for each day. Thus, hope and trust in God remain for longer. In the face of existence, time comes to be understood with great importance in the face of the nearness of death. It is because they are aware of their finitude, consequently of their physical death, that they present the urgency in the organization of pending before the remaining time for the closing of the life cycle.[2]

After analyzing the data, it became evident that the patients, after diagnosis of the disease, began to question more about the things they did and did not do. Then the regrets appear. From this fact, it can be inferred that they have had a busy life, work and obligations, and with the modification of the routine by the illness, they have more time to think and worry about the things that really matter in life. They live intensely one day at a time.

Before the interview, patients were questioned about different social aspects, which manifested the things considered most important in the process of illness in their lives, such as family support or even lack of it, as described in the following statements:

> *"Support of my wife, of my friends [...] I have my sister, my brothers who then so here, I have my sister that is technique [...] I felt that the family is caring more with me, I feel More dear [...] The feeling I have is that my niece, who is a nurse, it is difficult for her to come here and ask for me or ask me how I am, so she walked away, I do not know what happened, difficult [showed sadness during speech]."* (P1)

> *"Well, thank God, it's my children who take care of me, my husband. "I have nothing to complain about [...] but they are professionals who work in this area and they treat us with so much affection that bah, what I have for them is a lot of love and also related love. From the support of the family, I continue to have this support, it is wonderful for me. Everything we need, we need a hug, a care, that we have so much of you."* (P4)

According to the statements and observations, it is noticed that all the patients indicate the importance in having the support of the family, being that the P1 also relates the support of the friends. In spite of this, he misses the support of his niece, who showed sadness in talking about her. Faced with this need, the wife said that the patient had already spoken to her mother (sister) so that she (niece) would visit him, but that nothing happened and that she did not make much of a relationship with her uncle, and that the reason for the withdrawal is this. From that point on, it can be seen that the removal of a loved one can make the patient sad, and that their support is one of the best supports they can have in facing the disease.

P4 makes evident the importance of both family and health professionals. He also has a lot of family support, a really close family, to the point of the son with his wife and two children moving to their parents' house to help care for her. In addition to his daughter with the patient's granddaughter already living together in the residence. The family truly joined forces to help their father take care of P4. Very affectionate people among them and with us of the PIDI team, deeply welcoming.

After surgery, ten days later, the patient died. Death is still a source of fear for many people and health professionals. However, it is necessary to keep in mind the need and importance of providing dignity towards the end of life for patients and care while alive. Attitudes such as these can provide a sense of duty to the responsible professionals.

In this sense, it is evident that family support is extremely important so that the patient does not feel alone, abandoned. Thus, the family becomes our partner and collaborator, because it is perceived that these people have a better knowledge about the patient, their needs, their peculiarities, their desires and anxieties, which are sometimes not verbalized by the patient himself. In this sense, we know that these people also suffer or still get sick with the patient and their suffering must also be welcomed and palliated.[22]

Family support is essential for the patient, making them feel more loved, loved and secure among all, even in their departure, stating that they are not alone in facing the disease and not even in their death. This support is essential so that the patient can overcome their daily difficulties, facing them with a better quality of life, extending also to their caregivers/family members, who perceive the daily difficulties and difficulties that they are going through.

The health professionals who provide care to these patients were also mentioned in the statements below:

> *"They are very good, especially the nurses. The techniques that come here are great, were angels that appeared in my life too, treat me very well, the doctor who comes here, are great."* (P1)

> *"PIDI, Unimed and FAU, very good service, give support."* (P2)

> *"PIDI service is very good."* (P3)

> *"Wonderful, I have not even, oh, I have no words. They were all my friends, we even talk about Facebook [smiled]. PIDI, so I do not have to talk too, what a wonderful thing, I was delighted with the team, you do that beautiful job."* (P4)

> *"I think this is good, because I always hope that they [PIDI] will solve this here [fistula], I always hope, but I know it's difficult."* (P5)

In the above reports, it is clear that all patients have a good support from health professionals, who more evidenced the PIDI team, who provide a humanized care, guaranteeing them more comfort in face of their needs, social needs, Physical, emotional and/or spiritual. The P5, in addition to finding good PIDI care, as observed, refers to hope that the fistula closes, and thus lessens the discomfort and pain that it presents, since the team really tries and thinks of alternatives to provide greater comfort.

PIDI practitioners have the ability to follow these principles by assisting people who are facing this difficult phase of life, such as during the treatment of an illness such as cancer, which sounds scary to them. Each member of this team has its value, and everyone strives for the same common goal, which is to alleviate physical, psychological, social and spiritual symptoms, in which the autonomy of the person and his family in the home care is preserved.[23]

The PIDI team is able to take care of the patients' needs due to the multidisciplinarity that this team presents. The professional needs to be attentive to their needs, so that they can provide greater comfort and support for them and their families in the face of difficulties. A sensitive vision, a loving look, a touch, this is all very important and should be part of the care of patients. The professional, when involved, certainly obtains positive results in front of the needs that the patient and relatives present. In this way, these human beings come to be seen as a whole, and the reward that these professionals have is gratitude through the look, the affection they receive when they are beside them, and the learning they leave before the value of life. However, the PIDI team is essential for total pain relief, reaching all dimensions of patient and family difficulties.

Manifestations and physical needs

Manifestations related to the symptoms of the disease and the chemotherapy treatment became relevant through the reports below:

> *"Little way, I have a lot of pain to walk."* (P1)

> *"Days after [the surgery], I started with vomiting, vomiting, vomiting, could not eat anything else. The wife spoke to him (doctor), he said: now you have to start with the diet [...] the PIDI began to answer me, there it was passing [...]. Every once in a while we get well, sometimes we get in pain, we get sick, we get a little annoyed."* (P2)

> *"I lost a lot of weight, I stopped talking because of the tracheostomy, and I do not even taste the food [...] the symptoms I feel are the pain."* (P3)

> *"When it was one day I was in the bathroom, it seemed like I was going to faint, I could not take it anymore, it was such an unbearable pain [she cried a lot at the moment] [...] I could not pass that pain, then the husband had gone there in the PIDI, there they said they had no way to meet me because it was full, that only in 1 month, 2 months. I had to wait for them to have a vacancy, but that was too much pain, [...] without having the remedy to relieve the pain, and when it was the other day at 8 o'clock they beat up here. The other day in the early morning, the doctor said: from now on you will no longer go through pain [...] I was happy, even with the disease, not having pain for me is good, I am quite relieved."* (P4)

> *"It is this fistula that bothers me [...] the pain I feel is only when it is draining [fistula], otherwise it does not hurt."* (P5)

Regarding the above statements, it is noticed that the pain appeared in all cases, and undoubtedly, this symptom causes a very great discomfort, besides being possible to notice sadness in the patients' speech. Really, they have difficulties, that is, there are days when they feel good, with no complaints of physical symptoms, more hopeful, and other days they feel down, with physical symptoms like pain, nausea, among others. During a visit, P2 was sitting in his armchair complaining of nausea and numbness in his hands and feet. The other day, he said that a day ago he was very sick from chemotherapy, that when leaving the oncology sector he was driving and due to this symptom, he had to stop the car and give his wife drive home. Already another time, he said he was feeling good, with no physical ills.

As the speech of P4, it is evident how strong the symptoms and the pain can be. While observed, she showed at all times expression of pain in the abdomen, besides nausea, since in these days she could not feed well. The patient used fixed analgesia through opioids (morphine) as well as symptomatic pharmacological control and serum therapy

Signs and symptoms such as pain, nausea/vomiting, constipation, anorexia, dyspnea, anxiety, depression, agitation, insomnia, confusion, fatigue, dysphagia, oral lesions, pressure ulcers and immobility should be evaluated in order to discover the causes, Assessing whether they are primary to the disease in question or secondary to other factors, whether they are reversible or not. Contrary to popular belief, adequate diagnosis in palliative care is often the best way to manage a symptom.[24]

Pain is felt as a unique and individual experience, modified by the anticipated knowledge of an injury that may exist or presumed. However, in any situation, pain is what the patient refers to and describes. Before the evaluation of pain, the possibility of the patient talking about it is the starting point for the diagnosis, therapeutic implementation and subsequent evaluation of its effectiveness. In this sense, multiprofessional teams dedicated to palliative care should establish early clear communication routes for this evaluation, given the progressive, individual character, taking into account the sensitivity, emotional and behavior in the face of chronic pain.[25]

Patients in palliative care should begin treatment of symptoms as soon as possible. A previous approach is capable of preventing the symptoms and complications inherent to the underlying disease, as well as favoring the proper diagnosis and treatment of diseases that may accompany the main disease. A good evaluation based on the necessary examinations, besides the definition of the functional capacity of the patient are indispensable for the elaboration of an integral plan of care adapted to each case and adapted to each moment of the evolution of the disease.[22]

Reflecting on the category in question, it can be affirmed that the cancer greatly compromises the physical state of the patient, completely damaging the well-being of those people who are with the disease. In their case, without the possibility of cure, it is important that care might be established that aims to reduce these symptoms, the suffering that these people go through.

In this sense, palliative care becomes extremely necessary, since it promotes the quality of life of patients and their families through the prevention and relief of suffering. In addition, they contribute to an impeccable assessment and care of pain and other physical symptoms, since it is not only a medical treatment, since they are not efficient for all types of pain.

Manifestations and spiritual needs

According to the manifestations and spiritual needs, the patients spoke about religiosity, spirituality and faith. Therefore, on the beliefs they had before the disease, they reported that:

> *"A practicing Catholic [...] When I started to go to Mass, it was not the disease, it was well before, as I retired I had more time, right, we started going every Sunday."* (P1)

> *"A practicing Catholic [...] We always went there in Santa Maria, there is a church, the pilgrim is from there, it is a church that is always open, a convent of nuns, we always went there to pray."* (P2)

> *"Non-practicing Catholic."* (P3)

> *"Catholic non-practicing and spiritist [...] In the church like this I will not [...] Now I do not have more conditions, but when I could I went weekly, until last week I went there to take a little stroll in the spiritist center. I always went there once a week [...] My main religion is God, I believe in God a lot, I think God is in all religions."* (P4)

> *"I am Catholic, but I do not practice, I believe in God [...]. There have been other religions trying to help me, I believe in all of them, but I do not practice any."* (P5)

Through the lines, in all patients, religiosity is present, in addition to all being Catholic, P4 also mentions being a spiritist. In all patients there is this 'force majeure', belief in God, and this undoubtedly contributes greatly to the feeling of hope that they present. In addition to showing that it is one of the reasons that gives strength and courage to support cancer, something that contributes to a better daily life.

Religion has always been part of humanity, but nowadays human beings are increasingly turning to their religiosity/

spirituality in moments of suffering and moments of thanks for their achievements. However, it is clear that with the disease people often seek in their religion a meaning and a relief for suffering.[26]

It is important that the professional be with the chaplain, in face of a spirituality approach, in the prayers, and this kind of action can contribute to increase the patient's confidence in the team, bringing him more safety.[2]

During the interview, the patients also expressed their faith in the saints, in addition to the intensification of faith after the diagnosis of the disease, as follows in the following reports:

> *"I have Pope John Paul II as Saint, always had with me, I always bring his image, even when I went to do the operation, he was always together, there in my room [...]. Always when I was going to go into surgery I asked Mary to come forward, so I had this faith [...]. After the illness, the faith increased [...]."* (P1)

> *"[Faith] increased more [...]. For me, the most important part is faith and family. If it were not for them, I would not be able to [...], I always pray, I ask a few more years to stay with my son, to see him grow as he goes Growing up he's going to get better, he wants to see him get better, a better child, and my older son is studying, and his wife is in good health, that's why I feel like living, staying longer."* (P2)

> *"I have faith in Our Lady Aparecida, I carry her in my purse [...]. My faith in Our Lady appeared increased."* (P3)

> *"Once a year I go in the Procession of Our Lady Aparecida, I always go [...]. So I'm getting very attached to God in this difficult time, and so we get more of our religiosity, so I'm seeking God's strength to face this sickness and problems. We have a certain time when the agent gets a little bit like this, you forget a little bit of everything, you forget even to thank, and I saw in this everything that even this disease comes to awaken us, things that we should do and did not [...]. I have certainly thought more about God [...]. I am doing holistic spiritual that is through the word of faith, positive thinking, thinking that God will help me, that I will succeed, so this has helped me a lot."* (P4)

> *"There is a Saint who I really like is St. George [...]. I think it increased the faith, the desire to heal me [...]. [The cure] I ask, I always asked God."* (P5)

In the analysis of the speeches, P1 shows that he has faith in Pope John Paul II and in the Virgin Mary, and this was observed in his residence, since he has the images of these saints, and in another moment he said in an observation that he has faith too In São Jorge He showed me the prayer he carries in his wallet, said that always before leaving home he prays and has a lot of faith. Besides being surrounded in his room by the saints, there was a book titled Jesus on his side of the bed, and at that moment I questioned him about the book and he said it was good.

P2 did not mention the saints in the lines, but I noticed that in his residence he has the image of Our Lady Aparecida in the room, along with a third, which shows that he believes. P2 states that if it were not for the family and their faith would not be alive today, and that shows how important this is in their lives. Through the observations, I saw that the patient had at his side a rosary and a book entitled Jesus Can.

P2, P3, and P4 also demonstrated their faith in Our Lady Aparecida through their accounts, but I was also able to perceive the image of her in their residences, which affirms their faith in the Holy.

P4 calls attention when it says that it believes that the disease comes to awaken the faith. P5, like P1, also has its faith in St. George. In the room of P5 I realized that there is the image of the saint to whom he refers.

Also in the speeches it was evident that all the patients stated that the faith increased after the diagnosis of the disease, besides that P1, P2, P4 and P5 seem to be transitioning in the phase of the bargain, which has already been described in the text above. P4 and P5 have shown hope of healing when it comes to faith in God or the saints as evidenced above.

According to the reports, it is observed that spirituality shows itself as a support in facing the disease, and with the intensification of faith experience relief from their suffering, strengthening, improvement, trust and hope. In this context, faith becomes the support promoted by spirituality in order to provide a better balance of their emotions in the face of terminality through the sense of the presence of God, which is experienced by people in palliative care in different ways, Which are experienced through strength, love, faith, tranquility, protection, the possibility of overcoming obstacles.[2]

Therefore, spirituality is recognized as a link of positive emotions that has the capacity to promote the hope of the continuity of life, recognizing death as a natural process, that is, by the harmony felt in this force found in something supreme.[2]

According to what was said by the interviewees, religiosity, spirituality and faith contribute much to the confrontation of the patient's illness, and thus the hope that is often linked to the will to live. Faith is one of the necessities that brings peace and hope to these patients, strengthening them in the face of suffering and difficulties, being represented to them as a miraculous intercession. This is what they seek when they think of the cure of this disease that is so overwhelming in the lives of these people and of all those around them. Thus, the patient before nursing care should be seen as a whole, reaching all dimensions of this care, be it in the emotional, social, physical and spiritual aspects.

CONCLUSION

A disease like cancer undoubtedly changes the lives of patients and family members, altering the routine of all involved, and with it many feelings are generated, such as sadness, fear, anguish, hope, faith, among others. Caregivers begin to live more around the patient, who often feels guilty about relying on care, feeling that it disturbs the life of the caregiver, who has to give up many things in his life to take care of this Patient.

Participants, in addition to having their whole life modified with the disease, are now giving more value to moments with the family or with the people they love. They feel more secure, loved and need more of them. Before, because of the daily routine before illness, they did not have much time to be with the family, not because they did not want or did not love them, but because they needed to work, having in mind to help their family financially.

With the disease process, the patient begins to live one day at a time, and with that he has the time to solve 'his problems or his problems', whether to have someone's forgiveness, to redeem oneself of sins, to dismiss Of the most important people in your life or of doing or resolving your last wishes. For this to happen, these patients need to have the opportunity to talk about their feelings and wants. Nursing professionals need to be alert when listening to them, so that they can identify their real problems and consequently their needs met or resolved whenever possible.

These humans are still alive and need a lot of support to withstand the greatest pain, the greatest pain, the pain of the soul, as Dame Cicely Saunders said. This will certainly make the patient and their caregivers feel welcomed, safer, and better, as well as providing them with more dignity during this process and in the last moments of their lives.

Facing the reality with which these patients live is not an easy task, but it is capable of providing the nurse, or anyone who wants to discover, a good teaching about the true values of life. Undoubtedly, this was a wonderful experience that we had the opportunity to witness, despite seeing the suffering of the human being in the face of cancer and as soon as the death.

These people have the need of a loving look, with a simple touch, so that they are sure that they are not alone. Who says we cannot cling to them? Yes we can, only then will we understand them and give them the support they really need. We just have to learn from them. Giving the best of us brings us back to the sense of accomplishment. Even if we cannot save the lives of these patients, because that sometimes does not depend on us professionals, we can provide dignity to these people, which depends on us professionals, who can give them a good care while they are alive until their last breath.

According to the demands pointed out in this study, it is noticed that all need, and much, to be taken into account, since patients in palliative care reaffirmed the need for emotional, social, physical and spiritual support to care for their integral care.

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