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UNCERTAINTY IN THE FACE OF THE CANCER DIAGNOSIS

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ABSTRACT

Objective: describe the meaning of the experience in the face of the cancer diagnosis in the construction of the individual and subjective reality developed.

Method: qualitative study with a phenomenological-hermeneutic approach, developed at a cancer service, involving four women and two men with different cancer diagnoses. The interviews, collected between January and March 2016, were recorded. For the analysis, the Analysis of Interpretative Phenomenology and Mishel's Uncertainty Theory were employed.

Results: uncertainty is an experience that invades the patients with chronic illness. Themes emerge on lack of knowledge/knowledge; The health staff and family, support to cope with the diagnosis and not falter; Positive attitude; Suffering in view of adversity; Holding onto God and The adversity of the health system.

Conclusion: all patients experienced the period of uncertainty first as danger, but they made coping efforts, manifested by feelings of optimism and positive attitude, focused on reducing the uncertainty and controlling the emotional excitement their diagnosis aroused.

DESCRIPTORS: Cancer. Uncertainty. Qualitative research. Nursing. Chronic disease.

INCERTIDUMBRE FRENTE AL DIAGNÓSTICO DE CÁNCER

RESUMEN

Objetivo: describir el significado de la experiencia frente al diagnóstico de cáncer en la construcción de la realidad individual y subjetiva desarrollada.

Método: estudio cualitativo con enfoque fenomenológico hermenéutico, desarrollado en una unidad de cáncer, en cuatro mujeres y dos hombres, con diferentes diagnósticos de cáncer. Las entrevistas, recogidas entre enero y marzo de 2016, fueron grabadas y para el análisis se empleó el Análisis de la Fenomenología Interpretativa y la Teoría de la Incertidumbre de Mishel.

Resultados: la incertidumbre es una vivencia que invade a la persona con enfermedad crónica. Emergen temas acerca del Desconocimiento/conocimiento; El personal de salud y familiar, un soporte para enfrentar el diagnóstico y no desfallecer; Actitud positiva; Sufrimiento ante la adversidad; Aferrándose a Dios y La adversidad del sistema de salud.

Conclusión: todos los pacientes vivieron el período de incertidumbre en un principio como peligro, pero, emprendieron esfuerzos de afrontamiento manifestadas por sentimientos de optimismo y actitud positiva, dirigida a reducir la incertidumbre y a controlar la excitación emocional generada por su diagnóstico.

DESCRIPTORES: Cáncer. Incertidumbre. Investigación cualitativa, Enfermería, Enfermedad crónica.

INCERTEZA FRENTE AO DIAGNÓSTICO DO CâNCER

RESUMO

Objetivo: descrever o significado da experiência frente ao diagnóstico do câncer na construção da realidade individual e subjetiva desenvolvida.

Método: estudo qualitativo, com abordagem fenomenológica hermenêutica, desenvolvido em uma unidade de câncer, com quatro mulheres e dois homens, com diferentes diagnósticos de câncer. As entrevistas, coletadas entre janeiro e março de 2016, foram gravadas. A Análise Fenomenológica Interpretativa e a Teoria da Incerteza de Mishel foram utilizadas para a análise dos dados.

Resultados: a incerteza é uma experiência que invade os pacientes com doença crônica. os temas que emergiram da análise foram desconhecimento/conhecimento; A equipe de saúde e familiares, apoio para lidar com o diagnóstico e não vacilar; Atitude positiva; Sofrimento em vista da adversidade; Segurando em Deus e a Adversidade do sistema de saúde.

Conclusão: todos os pacientes viveram o período de incerteza em primeiro lugar como um perigo, mas após os esforços de enfrentamento manifestaram sentimentos de otimismo e atitude positiva, destinadas a reduzir a incerteza e para controlar excitação emocional gerado pelo diagnóstico de câncer.

DESCRIPTORES: Câncer. Incerteza. Pesquisa qualitativa. Enfermagem. Doença crônica.

INTRODUCTION

The leading causes of death from chronic noncommunicable diseases include cardiovascular diseases, diabetes, cancer and chronic respiratory diseases.¹⁻² Cancer is the leading cause of death in developed countries and the second cause in developing countries. The burden of this disease has increased as a result of population aging and growth, as well as the adoption of cancer-related lifestyles: smoking, physical inactivity and “westernized” diets.³ In the region of the Americas, it is estimated that 2.8 million people are diagnosed and 1.3 million die from cancer each year. It is predicted that, by the year 2025, new cancer cases will increase to more than four million and deaths to 1.9 million.⁴

Its diagnosis leads to moments of crisis, instants when not knowing about the disease and the process it means causes great uncertainty: Why me? What will happen to me? Am I going to die? Will I feel a lot of pain? Is my hair going to fall out? And my children? This represents a death sentence, mutilation of their hopes, a crossroads or, on the contrary, a greater desire to live and turn their life around favorably, in their new condition.

Uncertainty is “a cognitive state in which people are incapable of determining what the events mean that occur due to the disease”,^{5:225} deriving from a lack of stimuli and information, which do not permit cognitive processing of the facts related to the disease and building a meaning of these events. It can be seen as a danger while waiting for negative results, or as an opportunity, when one keeps up the hope that one’s disease will remain stable, adopting a new way and perspective of life.⁵

The framework of the stimuli, the cognitive capacities and the structure providers are antecedents of the uncertainty.⁵ The uncertainty the cancer diagnosis provokes can cause an emotional upheaval that hinders the timely initiation of the treatment or deficient treatment compliance, evidenced by the decreased capacity of perception, concentration and understanding of the information the patient receives about the disease management and treatment.

Applying this theory permits interpreting and understanding the uncertainty in order to guide the nursing care interventions. The previous evidence leads to the objective: to describe the meaning of the experience in view of the diagnosis of cancer in the construction of individual and subjective reality developed.

METHOD

A qualitative study with a phenomenological-hermeneutic approach was proposed, in which one seeks to contribute to the construction of reality taking into account people’s subjectivity, experiences and the meaning they attribute to them, “to find the meanings and understand their dynamics”.^{6:14} Reflection on the experience lived is always reminiscent, it is the reflection on the experience that has already happened or has already been lived.⁷

This study received approval in Bioethics Committee Certificate 7 of July 16, 2013, at the School of Health of *Universidad Surcolombiana* and institutional authorization for information access. Inclusion criteria: diagnosis of cancer, within a period not shorter than six months and not longer than one year, over 18 years of age, being treated in a cancer service in the city of Neiva-Huila-Colombia.

The information was collected between January and March 2016. After identifying each unit of information and after approving the informed consent, the data collection process was initiated through conversational interviews.⁸ The participants were contacted by telephone and interviewed at their residence, departing from the following question: How was your experience when you received the diagnosis of cancer? A script was elaborated to get deeper into the person’s experience. Each participant was interviewed only once, with an average duration of one hour each, recorded on tape. The research team transcribed the interviews verbatim.

Subsequently, the analysis was carried out through interpretative phenomenological analysis, in which the following steps are described: reading and rereading of the interviews, content analysis, identification of emerging issues, establishing connections between the themes, identification of interconnections between Interviews and search for common patterns.⁹ Pseudonyms were used to identify the informants.

RESULTS

The participants were between 24 and 36 years of age, with two male and four female patients. Three of the women were housewives and one was employed. Of the men, one was looking for a job and the other was a farm laborer. The diagnoses were as follows: two with testicular

cancer, one with breast cancer, one with ovarian cancer and two with cervical cancer. Based on the data analysis, in the framework of the Uncertainty Theory, six themes emerged (Figure 1): Lack of knowledge/knowledge; The health staff and

family, support to cope with the diagnosis and not falter; Positive attitude; Suffering in view of adversity; Holding onto God and The adversity of the health system.

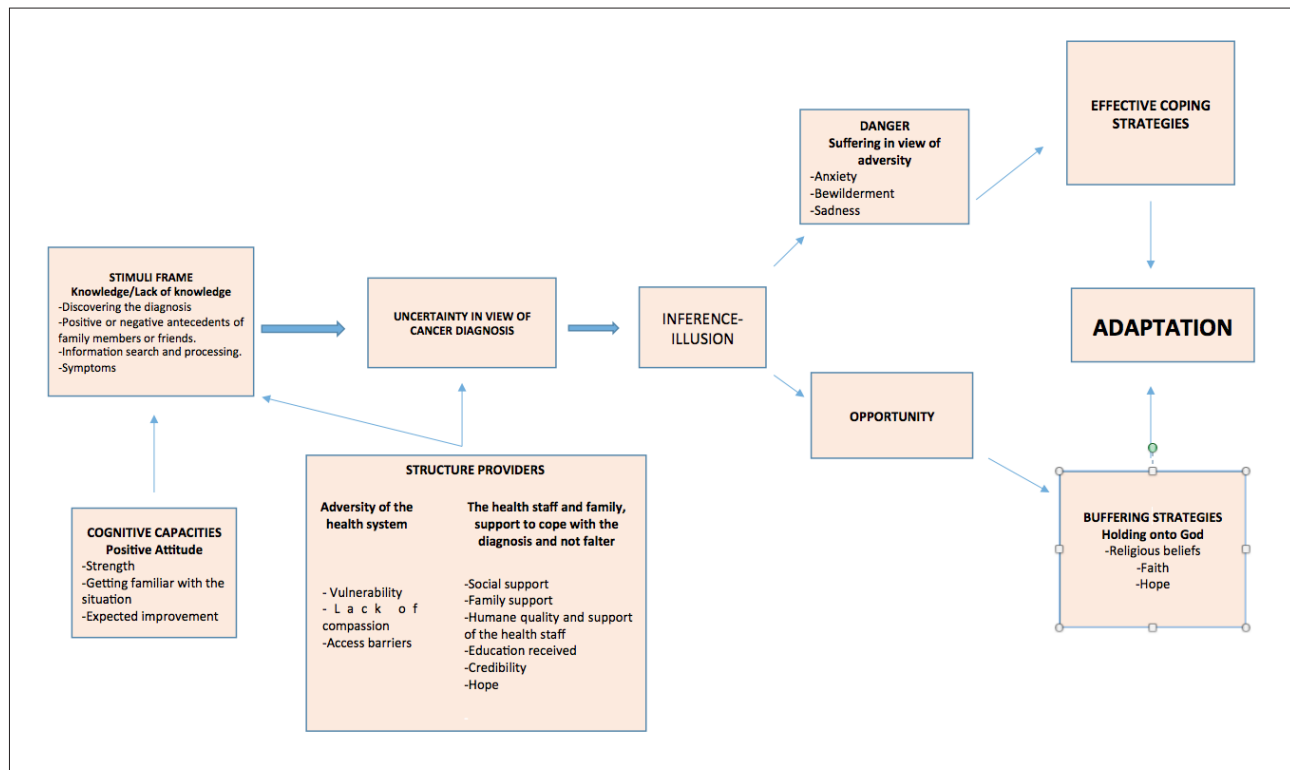


Figure 1 – Taken from *Theories of Uncertainty in Illness*.^{10:59}

Lack of Knowledge/knowledge

In some cases, the symptoms the disease produces delay the decision to consult the doctor. As they do not suspect cancer in principle, they are not scared. After the diagnosis is informed, however, they feel that everything changes, death is approaching, a feeling that deepens when there is a history of death by cancer in the family or relatives; leading them to experience frustration when they need to make difficult and unexpected decisions. Some of them start searching for information to know the severity of their situation.

Everything changed, I knew that surgery was coming and the chances of not being able to have a baby. I had the illusions of being a mom and then suddenly they were gone (María).

Not knowing anything about the subject did not scare me. And when we show the papers to the doctor, then he tells me: 'why did you linger so long, then I do worry' (Pedro).

I suspected that I had that, that things would go bad for me (Rosa).

That word cancer, one says death, I said: there, I'm done. My life is finished (Pilar).

Knowing the prognosis of the disease, hoping for the possibility of cure, despite the consequences (orchiectomy, mastectomy, hysterectomy), it's a reason to fight and get motivated to move forward:

I was very much on time, everyone told me, I saw that there was so much probability, it gave me hope (Marcos);

I asked the doctor, what are the chances of me being cured? - He said: 75%, it was little for me (Pedro).

After discovering the diagnosis, the participants state that the process from the beginning of the symptoms and the order of treatment is a race against the clock that does not allow them to assimilate the situation:

when I went to the doctor he told me, we need to move and do things fast (Pilar);

he said: with what you have, you need to act fast because, if not, it can expand to the other side (Pedro);

they held the medical meeting and they made the decision that they had to take everything out, I could not mourn because I am not able to get pregnant (María).

Finding out about other people's positive experiences helps to minimize the impact and helps to cope with the diagnosis in a way that allows them to face situations that may be considered inevitable:

one does not know the disease, but when one is with other patients, they infect him with that positivism (María);

being in contact with the other patients helped me to feel better, it changed my attitude (Pedro);

talking to other patients who lack a part of their body, about things of life, they have more life than one, I am more complete and I am complaining, I have to improve (Marcos);

no, there are many people who have been saved from cancer and I said ah! Well (Piedad).

The health staff and family, support to face the diagnosis and not falter

The support helps the recovery, promotes the reconstruction of life, decreases the harshness of the situation and makes the process more bearable. According to the participants:

the oncologist told me, you're not going to die of what you have, he sent me to the psychologist, and they channeled me and everything helped me a lot ..., all the people who are part of that process take care of you very well (María);

my oldest son, he did tell me, mommy, you are extraordinary, you are going to gain encourage so as not to let yourself die. The health staff is very special, humanitarian people, super friendly, they gave me all the hope of the world (Piedad);

the company, my parents and my wife, the attention of the health personnel, everything motivates a lot, the state of mind is 50% of the recovery from the disease, the peace and tranquility you have helps a lot (Pedro).

Positive attitude

Strength to move forward in the face of illness, pain or suffering makes them get accustomed to the situation, use the time as well as they can, help in the fight against crises and value every moment of life.

Hmmm I told the boss, well, I have cancer, but I came with my super wow attitude. It is stubborn, only

one who experiences it knows what one is going through but, anyway, one needs to draw strength from where one does not have any to move forward (Piedad).

Yes, my plans were others; but I said well, the ladies that I know are fine, me too, what matters is that you know how to take things (Rosa).

Having a positive attitude, I always used to say: 'I have nothing, I have nothing. Because if you say I'm going to die, the lighter that advances' (Pilar).

I was confident that I was going to get in and leave well; by the way, they gave me a very favorable prognosis (Marcos).

The attitude was always positive in the face of the disease, it motivates you a lot, partly the loved ones (Pedro).

The participants managed to confront the disease and develop effective coping strategies manifested when assuming a positive attitude towards the diagnosis, medical treatment and the prognosis of the disease.

Suffering in the face of adversity

Facing a diagnosis of cancer causes anxiety, bewilderment, despair, feelings of helplessness and worry in the participants when they sense what awaits them; on some occasions, they hide the diagnosis and their feeling of sadness so as not to generate pity; they perceive the disease as an obstacle to continuing their life project.

That is, it was very hard and it has been hard, I got depressed, I get there feeling very dull, the desire to cry came to me after leaving the doctor's office (María).

Terrible, that's stubborn, cancer is cancer ... I'm going to die, I felt very sad and I cried, I got depressed, I no longer put on make-up, I did not go anywhere, I walked around only in my pajamas. Why me? What happened? (Piedad).

It was terrible very painful, I cried every day alone so that no one would notice, because imagine you start crying and they also start crying. Sometimes I get depressed, but I pretend that nothing has happened to me, because imagine living like that all the time (Rosa).

They could not comfort me, like a crisis of depression, the more I cried, the more tears came out (Pilar).

I was shocked, I felt feelings of anger, frustration and anxiety about not knowing what was going to happen. Because to me, if I'm young, I'm just graduated and I'm going to start looking for work, getting into this, it was a surprise (Marcos).

I felt lost and angry at the time, I felt like that pressure in the chest, which is like a knot and crying relieved me (Pedro).

Holding onto God

Resorting to religious beliefs and holding onto God during the diagnostic process helps to face the reality and reduce the uncertainty seen as a danger. Adults choose this strategy more than young people, who reported that they do not stick to any particular religion and that they prefer to use alternative strategies in order to face the situation. The participants put their lives and their disease process in the hands of God. Faith and hope contribute to accept the reality and accept medical treatment with optimism.

One lives very grateful to God and begs him for help to move on (María).

I asked the Lord very much to please help me, not to leave me, not to take my life (Piedad).

I said, whatever God wants. You need to have faith (Rosa).

Now everything that God wants from me, I am not that devoted, but one nevertheless looks for the means to feel good (Marcos).

I was looking for strength in God, but I needed to get stronger myself, so if I stopped praying, I practiced a little meditation, the mind also needs its rest (Pedro).

The adversity of the health system

It is related to the accessibility to health services and the capacity to respond. In these aspects, the crisis of the system is evident, revealing the abandonment of the subjects who demand their attention, often turning them into objects and not subjects of care. Some are grateful to have friends in institutions, who influence their prompt care. Others need to turn to legal protection to receive the assessment and tests they require:

I was diagnosed with cancer in September, October, November, I was three months like that, they did not want to take care of me, until January, when we had to go to court (Piedad);

Then I started the process, turning, on the one hand, paying for a private biopsy, even though I had to go to court (Pilar);

It takes 90 or 120 days to see a specialist. Then there is a problem with your health insurance, as always the insurance there failing towards the patient. Everything takes a long time (Marcos).

It is important to note the impact of the information the person receives when the cancer diagnosis is informed; the coldness, lack of compassion and the expressions of imminent death is the health professionals' crude way of communicating. The lack of humanization and rapport with others is clear, which is the way to minimize the pain caused in view of the new situation they need to face, an event that discourages to move forward:

this is terrible! Dear God it is, and he started calling doctors and doctors and me there, well, more than half an hour with my legs open, it's not like I was a museum for everyone to be watching me. They all looked at me and looked at me, and said for God's sake! you have cancer, and you are super stubborn, there are very few women who survive this ..., he did not give me hope of life, those were very hard words, for me, that was terrible (Piedad);

unfortunately, what I have to tell you is that you have cancer. As he says vulgarly in my face. They told me that without anesthesia and nothing (Pilar).

the doctor tells me: you have to operate urgently, you have to remove a testicle, what you have is a tumor, it was like when a hot knife passes in butter (Marcos);

the doctor said that if we did not treat it that I could die, as if he wanted to intimidate one, that is, they give you that, that word of dying ..., when they give you the news they should not motivate you with threats but with recovery (Pedro).

DISCUSSION

The cancer diagnosis is a stressful experience and entails an enormous burden of anguish and suffering. The word cancer is associated with death, its mere mention triggers situations of anxiety in people.¹¹ They experience the uncertainty when they receive the diagnosis of the disease, arousing reactions people describe as "overwhelming", "impacting" and "incomprehensible".¹² In addition, it is considered as a psychological factor that affects many aspects of their life.¹³ The participants experience fear, denial, anguish, depression, doubts, which depend on the imaginary, the beliefs and the representation of what can happen to them: "imminence of death", making them perceive uncertainty.

Family care is a visible and simultaneously abstract multidimensional phenomenon. People consider that their family is close to them at that moment, but at the same time distant. This causes difficulties in the process as their desire is to get greater support from the family,¹⁴ which facilitates adaptation strategies and reduces uncertainty. In this same sense, social support prevents the uncer-

tainty. Interacting with others helps to clarify the situation and to constitute a cognitive scheme.

Social and cultural factors the patient lives in can affect the experience of uncertainty in the face of the disease.¹³ Additionally, when the process is not clear and the doctors and other health professionals answer the patient's questions ambiguously, uncertainty increases.¹³

After the person hears the word tumor or suspicion of cancer, he feels curious to consult on the subject. Internet searches are the main source of information they have. A broad spectrum of attitudes is found, ranging from those who have deliberately decided not to consult information to other people who spend a large part of the day looking for additional information. They expand their knowledge about their illness, alleviating situations of uncertainty or anxiety thanks to the information they receive, for example, by other people affected by the disease.¹⁵⁻¹⁶

For the participants, knowing the positive experience of others helps to cope with the diagnosis. This identification among patients helps to minimize the impact of a disease that is considered terrible and improves the disease management.¹⁷

The feeling of empathy because they went through the same traumatic event facilitates the effectiveness of these peers as information providers. The person self-assesses the uncertainty, uses inference¹⁸ through the identification of similar situations. When these situations are positive, the uncertainty is evaluated as beneficial and they build a positive system of beliefs, maintain the illusion¹⁸ that protects them to move forward, looking for adaptation and balance in their lives.

The uncertainty decreases as the patients' level of knowledge about their illness increases. The information and training offered to the person translate into cognitive reformulation, which reduces the uncertainty.¹⁹ The health professional, especially nursing, as a source of structure needs to provide clear, accurate, necessary and sufficient information to the individual, which allows him to understand the new experience he is going through. Interpreting the framework of stimuli and elaborating the meaning of what happens makes it easier for the person to structure a scheme that creates less uncertainty.²⁰⁻²¹ Providing people with proper levels of information, involving them in making decisions according to their level of commitment and discussing present and/or future care according to their needs contributes so that health personnel can individualize the care for these people.²²

Nevertheless, as a result of the way the medical staff communicates the diagnosis, it is perceived as imminent death, generating uncertainty. The impact of the news also depends on the way in which the communication takes place.²³ Having broader access to information, diminishing the obstacles in the communication with the doctors and giving patients the opportunity to participate in the decision making can reduce their uncertainty, which in turn would improve their quality of life.²⁴

The establishment of satisfactory medical relationships contributes to providing information that allows the patients to easily understand what their condition is and effectively influences treatment compliance.²⁵

The study shows that there is a shortage of doctor-patient communication that contributes to generating uncertainty. The way of communicating with the patient varies among the medical professionals. There is no established protocol to inform this diagnosis, which permits strengthening the communicative competence. The improvement of communication and the management of the information the health staff provides to the patients is relevant for the development of the healthcare practice, as it contributes for the health teams to cope with and decrease the uncertainty.

The word cancer undermines the existence. This suffering is greater when there is no proper doctor-patient communication. The suffering the patient experiences is directly related with: how did they tell it? Communicating the truth "brutally" produces the same harm as lying. The person has the right to know his situation and the doctor has to be truthful in the information, recognizing the individual's emotional and cognitive condition.²⁶ People identify how they sometimes feel vulnerable in the presence of the health staff, especially in situations where they feel exposed. They perceive disequilibrium between themselves and the health personnel, which is why they feel that it is important to maintain their self-determination and integrity. The existential uncertainty is acknowledged during medical care encounters, characterized by clear power imbalances.²⁷

In addition, the concern with administrative proceedings adds up to the uncertainty of knowing that one has cancer. The most difficult barrier to overcome is the timely access to the physician and diagnostic tests, giving rise to claims to permanently guarantee the treatment. The patient goes through this experience of being obliged to go from one side to the other, like a true nightmare; at

first, the lack of information, the red tape and the access barriers the health system raises increase the patients' uncertainty, evidencing the perversity of the health system, which distances them from the humane context.

Structural barriers have been found for women with breast cancer to have access to services, such as socioeconomic status, ignorance of rights and social discrimination by insurers, which makes them turn to legal entities.²⁸

The health system evidences its inequities, increasing the access barriers and perpetuating the suffering the subjects who demand their services end up in. The patients notice that having friends or relationships in companies is a fortune. Unknown people who face the uncertainty the functioning and fractioning of the health system causes do not have the same luck. The patients demand agile and accessible services in relation to professional care, they expect interest, understanding, empathy and communication skills.²⁹

In response to the confusion and disorder the state of continuous uncertainty causes, the system has no choice but to change to survive.⁵ Different degrees of adaptation were shown in the patients, which led to a decrease in their uncertainty, in which "how they told you", "family and health team support", and "holding onto God" played a predominant role. In this sense, people describe four strategies to control the uncertainty they find themselves in: God, the person, the company of God and the person, and the government.¹² The coping the patients experienced was manifested by feelings of optimism and a positive attitude.

Adaptation represents the continuity of the individual's normal bio-psychosocial behavior and the achievement of the desired outcome through the coping efforts. This serves to reduce the level of uncertainty, seen as a danger, or to see uncertainty as an opportunity, even developing a new perspective on life.

The uncertainty theory considers the person as a biopsychosocial system that is normally far from a state of equilibrium. The uncertainty invades almost all the aspects of the being's life, who passes gradually from denial to the acceptance and assimilation of the disease as part of his reality. Thus, the person maintains a state of health and well-being.⁵

In this research, the patients managed to face the diagnosis of cancer supported in the first instance by the family, loved ones and the health team, with the participation of the nursing staff. Their function¹⁸ is to help interpret the facts the dis-

ease has led to, approaching the understanding of what is happening to those persons. In this process, holistic nursing care plays an important role, aiming to empower the individuals to favor the development of positive strategies in the construction of the reality of their illness.

It is important to highlight the limitations of the study results in terms of generalization given the qualitative method used. Nevertheless, this contributes to the knowledge on the theme studies and permits the development of future studies, with methods that permit the generalization of the results.

CONCLUSION

Receiving the diagnosis of cancer is an experience that generates uncertainty in the people. It should be kept in mind that the persons facing a diagnosis of cancer are holistic and constantly evolving beings, who require qualified support from the health staff, especially the nursing personnel, to enhance their ability to adapt.

For these persons, this type of news involves their entire existence and they face their finitude generating uncertainty, which can range from a negative evaluation to starting a new life project.

The communication of the diagnosis should involve an interdisciplinary team that provides effective support to the individual and his family. The patient's knowledge about this disease should be explored, what he desperately wants to know. An appropriate space is needed to provide the diagnosis. It is important to acknowledge that, sooner or later, human beings face the end of life. Therefore, it is transcendental to dignify each stage the human beings face during their illness, building a space of peace and harmony in the environment and thus diminishing the pain the disease causes them.

The lack of or improperly provided information contributes to generating uncertainty in the person and, therefore, can be evaluated as a danger or as an opportunity. Uncertain events assessed as danger involve harm or damage. Nursing urgently needs to determine the factors that influence the uncertainty and help reduce it through clear and precise education, contributing to positive coping.

This study is relevant for nursing practice. Through the application of the Uncertainty Theory, we can identify the uncertainty in the face of the diagnosis of cancer and it becomes a mechanism that drives patients to see the disease as an opportunity and to implement strategies towards their

adaptation. In this same sense, transforming the disease-oriented care and building care focused on the human being represents a challenge. This facilitates the implementation of policies in the health services to provide support to people facing the cancer diagnosis.

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