

Experiences of caring for cancer patients after chemotherapy

Summary

Introduction: Cancer is the second leading cause of death in the world, it has resulted in 8.8 million deaths; that is, one in six deaths are due to this disease, among the consequences of suffering from this disease, is the psychological impact that affects not only the person, but also his closest family and social environment. The experience of living with this disease and receiving chemotherapy treatment, generates multiple changes that the patient, most of the time, is not prepared to face; especially when care is provided at home.

Objective: Describe the experiences of cancer patients about home care, post-chemotherapy.

Methodology: Qualitative approach, in-depth interview technique and participating observation were used; interviews were conducted up to theoretical saturation. The population consisted of 6 participants with different diagnoses of cancer. The thematic content analysis method was used for the interpretation of the information. **Results:** The analysis identified 399 live codes, 27 subcategories and 5 categories: 1.- Experiences of living with cancer and chemotherapy; 2.- Home care experiences; 3.- Family care experiences; 4.- Experiences of care of symptoms of chemotherapy; 5.- Experiences of care change of attitude in the face of chemotherapy.

Conclusion: The experiences they develop throughout this process are emotional and physical changes; stop doing their daily activities and face family and economic challenges involving the acquisition of medicines and the side effects of chemotherapy; they also seek to know more about the disease itself and how to minimize its effects.

Keywords: maintenance chemotherapy, life change events, nursing, continuity of care, physical changes, family, psychological impact, muscles

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Introduction

Cancer is the second leading cause of death in the world, it has resulted in 8.8 million deaths; that is, one in six deaths is due to this disease.¹ Among the consequences of suffering from this disease is the psychological impact that affects not only the person, but also his closest family and social environment.² The experience of living with this disease and receiving chemotherapy treatment, generates multiple psychological, emotional, physical, family and work changes that the patient, most of the time, is not prepared to face; especially when care is provided at home.³ Situation that generates, among other things, stress; also feelings such as fear, loneliness or anxiety; changes caused by the application of chemotherapy. In this sense, people living with cancer face new challenges such as: managing outpatient chemotherapy, tracking symptoms for the side effects that it can cause; Guell, states that the onset of side effects depends on the chemotherapy administered and the patient himself, that is, the functional state of the organs; the side effects of chemotherapy are many and very derived, as well as the care needs that generate.⁴

The American Cancer Society mentions that the most common side effects are: tiredness, hair loss, tendency to easily develop bruising and bleeding, infection, anemia, nausea and vomiting, changes in appetite, constipation, diarrhea, problems in the mouth, tongue and throat such as ulcers (sores) and pain when swallowing; problems in muscles and nerves such as numbness, tingling and pain; changes in skin and nails, such as dryness and change in tone; urinary changes and kidney problems, changes in weight, effect of chemo brain that

affects the ability to concentrate and focus, mood swings, changes in sexual desire and function, as well as fertility problems.⁵

Consequently, health personnel would have to facilitate continuity of care (CC) for these patients throughout the process, as these people need to understand changes and side effects during the treatment of chemotherapy, therefore, CC is the activity described according to Lagoueyte, Gómez MI, as the level at which health services are connected and consistent with the patient's health needs and personal situation in order for the person to have sufficient information, taking into account that care must continue at home.⁶

That is why nursing professionals should be familiar with the experiences that cancer patients have undergone in chemotherapy treatment, in order to deepen the experiences they present and thus advance in the analysis of the relationship of these phenomena in order to build evidence of the need to implement continuity under the scheme to improve the quality of life of these people,⁷ hence the following objective arises: Describe the experiences of cancer patients about care in their domicile, after chemotherapy.

Methodology

The research was conducted using the descriptive qualitative method; the in-depth interview technique and the participant observation were used, the interviews were carried out until theoretical saturation. Descriptive because it allows an investigation that preserves the holistic and the characteristic sense of real life events, it focuses on the causes of the study, of a critical nature,

given the peculiarity of the subject and object of study, which makes the study unrepeatable and its revealing nature, because it allows to demonstrate to the scientific community, a study that would not have been possible to know otherwise.⁸

The researcher was based on a semi-structured interview and narrative records that were stored in audio for later transcription and analysis so as not to lose details of the speeches and thus establish an approach to open coding through categories, MAXQDA version 18 software was used, which allowed the coding of the relevant data. The inclusion criteria were: adult men and women suffering from cancer, who attended the outpatient clinic of a second level hospital, the sample was selected using the snowball technique, which consists of selecting individuals to be studied, in the same way, they recruit new participants among their acquaintances, so the sample size increases during development,⁹ the interviews were conducted in the months of October to December of 2018.

Procedure: Authorization was requested from the authorities of the Hospital where the selection of the participants was carried out, the patients were adults with cancer, both sexes, aged 30 to 60, who received outpatient chemotherapy treatment (intravenous) from three sessions and who agreed to participate voluntarily, with prior informed consent, after explaining the purpose of the investigation to be carried out. They were described how the interview would be conducted and how they would participate in it. Subsequently, the investigation began, the duration and the material that was recorded lasted an average of one hour and a half. The interviews were conducted in the homes of the participants, it was ensured that the environment remained silent and that the place had good lighting to carry out the interviews without interruptions.

The method used was thematic analysis, which provides a flexible and useful research tool, which can potentially provide rich and detailed data. Thematic analysis is a method to identify, analyze and report patterns (topics) within the data. Using the 6 phases, 1: familiarize yourself with your data, 2: code generation, 3: topic search, initials, 4: reviewing topics, 5: define and name topics, 6: report production. Which allowed to give an order to the investigation.¹⁰

The material that was recorded was transcribed in Office Word, as close as possible to the event of the collection of the information and was carried out in a reliable way; this material is part of the reports of the interviews. The observations and comments of the participants were recorded, as well as their reactions in the individual interview; These records were also protected to protect the integrity of the participants. Data collection instruments: The main instrument of inquiry was a semi-structured interview; to learn about the experiences of cancer patients after chemotherapy; in which a generating question was asked where the question to the study participant was: What has been your experience of care regarding your chemotherapy application?, as well as a question guide that was divided into care experiences, changes of the person with cancer and chemotherapy experiences.

Ethical Considerations: Qualitative research was based on criteria of rigor, credibility, applicability and relevance as set forth in the Regulations of the General Law on Research Health,¹¹ as well as informed consent to cancer patients.

Results

Semi-structured interviews were conducted with patients suffering from cancer, 6 adults, aged 30 to 60, of which 4 were women and 2

men, all without work activity and with the beginning of the third cycle of chemotherapy, three women with cancer breast, a woman with ovarian cancer, a man with lung cancer and the other male participant with prostate cancer; three with a professional career and three with a high school completed, each of the interviews had an average duration of approximately 90 to 120 minutes and 112 pages were transcribed in total. The thematic analysis allowed to identify 399 living codes, 27 subcategories and 5 categories, which are presented below.

Category 1 experiences of living with cancer and chemotherapy

The majority refers to the production of a series of emotional changes, the fear of initiating an aggressive treatment of which they were informed by the medical area and consequently the ignorance of home care. Cancer patients who undergo chemotherapy treatment, have a radical change in their lives, most when they learn about their diagnosis, the first thing they experienced was the fear of the unknown, what would happen to them, without taking any importance in that moment to the care that they would initiate at home, the emotional changes that were present at that time were more important for them, this finding agrees with the exposed in the qualitative investigation of Jaman-Mewes³ who affirms that the changes that chemotherapy produces, are constant emotions of multiple changes. The following discourses arise in the narrative:(....).

“When you hear you have cancer, the world collapsed, I did not know what to do, and then to say that the treatment, then, the only treatment is chemotherapy, apart from that they already operated on you they already gave you radios and that they tell you only chemotherapy but no Sure, if you are afraid of dying and then the health staff thinks that you know everything, because they do not inform you (.....) but when you feel chills, bone pain, disgust, so you learn even the names of the medications that are going to you To help control these discomforts, it is difficult to learn what to do in case you feel bad at home but I tell you, after how you feel, you ask, but you do not understand what the medicines are for (.....) Then you even prepare so you don't feel so bad ”(....) PH2, PM1, PM4.

On the other hand, three of these six participants, due to chemotherapy, had complications, which had to be hospitalized for fever.

(....) “Miss, it was enough with the first chemotherapy to get to the hospital, I'm almost dying! I don't tell you, it was, they say, a very serious infection, so at home, what could I do? if this was serious at least I arrived on time, but I don't tell it; This experience was horrible! so they informed me that I had to take care of myself even in places where there are many people, because even a simple flu could kill me ”(....) PM1, PM3, PH2, PM5.

Category 2 home care experiences

Most report that the changes that have marked them the most, are not the physical changes, but living with cancer and chemotherapy, because they can no longer carry out their usual activities, hence the importance of giving continuity of care to these people and that this continuity is applicable throughout the entire evolutionary process of the treatment of chemotherapy and its different stages, and not only in the advanced stage; that is, in terminal patients. This continuity must be present from the diagnosis, as Valentin et al.¹² refers. For this category the following speeches arise:

(...) “What affected me the most was leaving my job, stop seeing my friends, my relatives, I don’t drive anymore, now I spend sleeping and disgusted, now weight loss; hair loss, and no longer wearing makeup is no problem, I just look in the mirror and ... (laughs), nurses tell me to better rest, if, then, there is no other; then I better sleep and sleep in my house” (....) PM1, PM3, PM5.

Category 3 family care experiences

In this category, living with cancer and chemotherapy is a challenge, not only for the patient but also for the family, to carry out care for the participant in the home is to face the unknown, to experiences that gave a change of life to all, the following speeches are narrated:

(...) “My family is my support, my daughter who is already married has to stay to watch me after chemotherapy; I say no because the symptoms that attack me the most are when three days pass, when I get dizzy, the iron taste, I don’t want to smell anything or give me headaches; Poor of my children! They are on the lookout for the medications they touch me so that I don’t miss the time, I tell their colleagues: they should attend at home ... Nothing like you who knows what to do!; I did not know that eating ice was good for me not to dehydrate, so here in the case I have many things that help me” (....).

The meaning of changing habits, being with chemotherapy, no longer living with family and friends also led to changing roles and it is for the heads of families who now have other priorities.

(...) “I do not want to depend on my children, but now I have no choice. What do I do? if I can no longer work and some medicines I have to buy them; my children apart from taking care of me, they give me money, they are investigating the doctors who check me and my wife is now in charge of what I used to do: that the light, that the phone, that the school meetings; Even she has to go for my medications!, the disease forces me to almost not move from my house” (....) PH2.

Category 4 experiences of chemotherapy symptom care

The experience of going to chemotherapies was difficult at the beginning, being repetitive helped to get used to it, but the attention of the symptoms in the home was difficult for most, to understand how to deal with the different symptoms by chemotherapies.

(...) “It is difficult to handle most of the symptoms, sometimes here the nurses tell you little by little what will happen, and you know the medications they give you ... and you come to your house and you’re just waiting to see what do you feel; You would like to have the nurse here! Then you also want you to fall asleep very deeply and the next day you would feel good, but not miss; You really feel worse! You know that there are herbs and natural aloes that you learn to use by necessity... (laughs) a drug to calm the pain, you use everything! It is also not prohibited! I already took up the Chinese beetles!” (...) PH2, PM4, PM1 .

(...) “The first chemotherapy according to me almost did not give me a can, but the second ... Do not invent !, (sadness) gave me a tremor that gave me no time to talk to my daughter; If not for the neighbor who helped me call the ambulance, and already in the hospital they told me that since I started the fever I had to go to the emergency room, and then they explained to me that I had to learn to take the temperature; little detail that I never asked and that they didn’t tell me

either; but hey ... now I’m on the lookout and I’m not alone at home anymore; Now I look small that they have to take care of me and I also learned to take care of myself, like what not to eat and what if to eat, the medications, I even have a diagram of my medications that I have to take and I already know how to take the temperature, I even bought a baumanometer How do you see? ”(....) PM3.

The majority of the participants referred to the complexity of understanding the indications of the health personnel for the follow-up of care in their home, and also coincide with the claim of being more humanistic when attending to their needs.

(...) “At the beginning I did not understand anything; I even remember that my doctor scolded me because, I think I could not explain that the drug was not found in the pharmacy and well: You think we studied the same thing! I needed a medicine for vomiting, it was not ranitidine; it was another that had the name of Ondansetron, but no, the one who gave us had another name, until my daughter asked several nurses and they told us that it was the same, but I did not believe I asked her and he got upset; and well, sometimes you feel sick sometimes, and then the face of few friends of your colleagues; not all, I clarify, but oh God! they would have to be more humanistic, hopefully their research would reach all the staff that is in charge of people like me .. (Blushing) ”(....).

On the other hand, Palacios, González and Zani (2014)¹³ in their study of social representations of cancer and chemotherapy in cancer patients, sought to understand the meaning of the cancer patient with chemotherapy, showing that when they receive chemotherapy they become familiar and cease to be strangers, to clarify that both are suffering and death threat; in this sense, cancer and chemotherapy involve the same management, and the patient faces it according to the care experiences that they are living day by day; In this investigation the participants admitted that the symptoms helped to improve the use of the drugs and also the care at home they learned according to the situations in which they needed them.

Category 5 experiences of changing attitude care towards chemotherapy

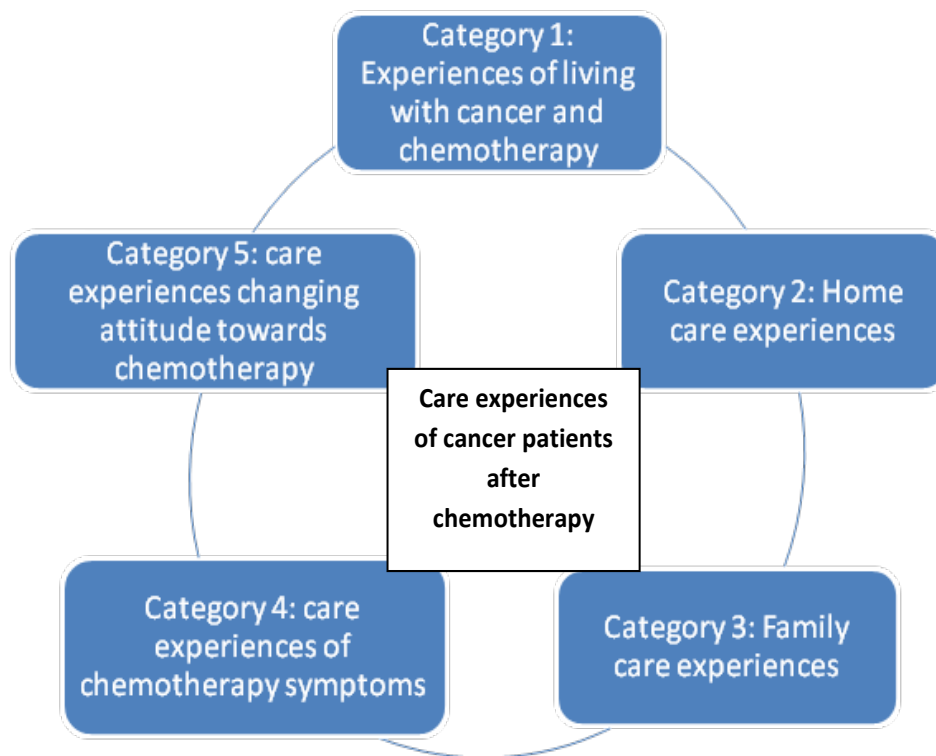
The experiences of living with constant changes by chemotherapy have allowed them to reflect and become aware of living in the hope of beating cancer; despite the symptoms that it causes them; Home care for the majority is experiences that express others, their chemotherapy partners who arrive for the first time.

(...) “I want to live! Everything has been very difficult, but I have faith in God that everything will happen, and I have informed myself a lot; I look for information on the internet, we are no longer to ask Why me ?, If I do not understand how it happened to me, I better ask: What else can I take to feel better? something else, I don’t know more! tell my experience to others that the same thing is happening to them, and express what to do if they show the symptoms; I do not know, tips so that they are prepared because who can hold so much chemicals in the body?, because that is chemotherapy, chemicals that kill you bad and good cells, everything you learn as it happens to you” (....) PH2, PM4, PM1.

(...) “I do not wish anyone this ugly disease, but now it is no use that the psychologist listens to you, but nothing like explaining to people the same thing happens to them; I am very asked and so I learned much more than with doctors or nurses; Better those who were in chemotherapy asked them what it felt like and what they did to take

care of themselves at home. Even family members also asked them things! So I also discovered the pharmacies that give you cheaper medicines. So you learn to take care of yourself and you face the ugly disease better; I hope this nightmare happens very soon" (...) PH6.

Outline of care experiences of cancer patients after chemotherapy



Discussion

Cancer patients who undergo chemotherapy treatment have a radical change in their lives; When they found out about their diagnosis, most of the people, the first thing they experienced was the fear of the unknown and what would happen to them, without giving importance to the care they would start at home; The emotional changes that were present at that time were more important for them, this finding is consistent with what was stated in the qualitative research of Jaman-Mewes³ who states that chemotherapy produces multiple changes and functional, emotional and spiritual body symptoms. The same author mentions that patients seek new approaches to care such as alternative medicine and the internet search, says that due to existing technology, implementing a system of care by this means can serve to stay in touch with the nursing team, clarify doubts and share experiences, opinions that also coincided with this research.

On the other hand, the study by Palacios-Espinoza et al.² evidenced that cancer and chemotherapy involve the same management and the patient faces it according to the care experiences he is living day by day, in this research the participants admitted that the symptoms helped to improve the use of the drugs; as well as learn the care they should have at home, according to the situations in which they needed them. The results of this research show that Continuity of Care (CC) is not implemented in our Mexican context, which should be applied throughout the entire evolutionary process of chemotherapy treatment and its different stages. This CC must be present from the diagnosis as

it refers to Valentin et al.¹² On the other hand, the finding of distance from the nurse-patient relationship impoverishes the orientation of care; Therefore, the oncological patient nurse relationship must be the central point to understand and qualify the care practices of this population.

Conclusion

The categories allowed describing the experiences that the patient is experiencing, which are evident with his personal accounts, which were confirmed with the literature. The experiences they develop throughout this process are emotional and physical changes that lead them to think about the idea of dying; also accept the idea that they should stop performing their daily activities and face the family and economic challenges involved in acquiring medications and the side effects of chemotherapy; They also seek to know more about the disease itself and how to minimize its effects. They also report that the CC that should provide nursing is absent, since patients are experts in their care based on their symptoms, their own experiences and other patients who serve them to know and plan home care; Therefore, it is concluded that it is necessary to give more personalized, humanized care and implement continuity of care at home based on people's experiences.

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Conflicts of interest

The author declares there is no conflict of interest.

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