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Man's experience facing illness due to cancer: implications for health care

Vivência do homem diante do adoecimento pelo câncer: implicações para o cuidado em saúde

La experiencia del hombre frente a la enfermedad por cáncer: implicaciones para la atención en salud

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Abstract: Objective: to understand how men experience the process of becoming ill with cancer, from diagnosis to treatment. **Method:** a descriptive, exploratory and qualitative study, conducted with ten men undergoing cancer treatment, in a municipality in the interior of Minas Gerais, between March and May 2017. Data were collected from recorded interviews, later transcribed in full and submitted to thematic analysis of the content. **Results:** two categories emerged: "The discovery of diagnosis, the treatment and the changes in daily life: coping and resignification" and; "The care offered by the health team". **Conclusion:** the experience of an oncological disease is permeated by denial, anger, anguish, sadness and fear. The man faces the possibility of death, threat to his future and has difficulty adapting to his new life. Family, friends and health professionals are important for the control and coping with the disease.

Descriptors: Neoplasms; Men's health; Nursing; Psychological adaptation

Resumo: Objetivo: compreender como o homem vivencia o processo de adoecimento do câncer, desde o diagnóstico até o tratamento. **Método:** estudo descritivo, exploratório e qualitativo, realizado com dez homens em tratamento oncológico, em um município do interior de Minas Gerais, entre março e maio de 2017. Os dados foram coletados a partir de entrevistas gravadas, posteriormente transcritos na íntegra e submetidos a análise temática do conteúdo. **Resultados:** emergiram duas categorias: "A descoberta do diagnóstico, o tratamento e as mudanças no cotidiano: enfrentamentos e ressignificações" e "O cuidado oferecido pela equipe de saúde". **Conclusão:** a vivência de uma doença oncológica é permeada por negação, raiva, angústia, tristeza e temor. O homem se depara com

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possibilidade de morte, ameaça ao seu futuro e dificuldades para se adaptar à nova vida. A família, amigos e os profissionais de saúde são importantes para o controle e o enfrentamento da doença.

Descritores: Neoplasias; Saúde do homem; Enfermagem; Adaptação psicológica

Resumen: **Objetivo:** comprender cómo los hombres experimentan el proceso de la enfermedad del cáncer, desde el diagnóstico hasta el tratamiento. **Método:** estudio descriptivo, exploratorio y cualitativo, realizado con diez hombres sometidos a tratamiento, en un municipio del interior de Minas Gerais, entre marzo y mayo de 2017. Los datos fueron recolectados a partir de entrevistas grabadas, transcritas en su totalidad y sometidas al Análisis Temático de Contenido. **Resultados:** emergieron dos categorías: “El descubrimiento del diagnóstico, el tratamiento y los cambios en la vida cotidiana: afrontamiento y nuevas significaciones" y; "La atención ofrecida por el equipo de salud". **Conclusión:** la experiencia de una enfermedad oncológica está impregnada de negación, ira, angustia, tristeza y miedo. El hombre enfrenta la posibilidad de la muerte, amenaza a su futuro y tiene dificultades para adaptarse a su nueva vida. Familia, amigos y profesionales de salud son importantes para controlar y hacer frente a la enfermedad.

Descriptores: Neoplasias; Salud del hombre; Enfermería; Adaptación psicológica

Introduction

The word cancer is often used to define a set of over one hundred tumors that have in common, the disordered and accelerated growth of cells that can invade tissues and organs, spreading to other areas of the body.[1] Despite advances and investments in public policies aimed at prevention and early diagnosis, cancer is still one of the leading causes of death in Brazil and in the world, with greater mortality in the male public, which reveals the implications of genre in setting this scenario.[2]

It is noteworthy that socially established conceptions and values make it difficult for men to access health care practices, so they delay going to referral services and only seek help when they can no longer support and cope with symptoms. Consequently, they often have to face a late diagnosis with repercussions on quality of life,[3] This is because caring for oneself and others is still socially recognized as a natural attribute of women. Thus, when approaching care actions, men risk having the authenticity of their masculinity questioned by the social group itself.[4]

In this direction, it is observed that the assistance proposals meet this culture established in society; Thus, health services are designed, structured and implemented with a greater emphasis on the health needs of women, children and the elderly, leaving little room for recognizing the specific demands of the adult and young male population.[5] Considering the health problems related to males as public health problems, the National Policy for Integral Attention to Men's Health, implemented in 2008, aims to expand and improve the access of this population to health services, ensuring quality care since prevention until the treatment of cancer.[6]

For this, governmental efforts are needed to encourage the development of actions to mobilize the male population to adhere to prevention and self-care actions, as well as to broaden the development of proposals that involve men's understanding of late search for health services, transcending individual blaming. It is also important to elaborate health promotion strategies that consider the singularities and specificities of this public,[5-7] since male-specific public policies were not formulated in the same proportion as those aimed at other social categories.[7]

It is also worth mentioning that the theme of cancer prevention among men has been restricted to neoplasms that affect the genital and urological system, reflecting a gap regarding the production of knowledge about the prevention practices of other types of cancer, which also have a high incidence among men, such as lung, colon and rectum, stomach, oral cavity, esophagus, bladder, larynx and leukemias.[7]

In this sense, the production of knowledge regarding the process of illness of men by cancer and the implications in their daily lives has gaps and often the productions turn specifically to prostate cancer. This assertion indicates the need for further studies that address the repercussions of cancer on men's lives to rethink how health policies have reached this public.

Thus, it is important to enter the reality of the man facing cancer and its consequences, in a society that typifies man as strong, healthy and productive. The mobilizing question of the research was: How does man experience the process of cancer illness, from diagnosis to treatment? Thus, the present study aims to understand how men experience the cancer disease process, from diagnosis to treatment.

Method

This is a descriptive, exploratory study with a qualitative approach. The research scenario took place in a municipality in the interior of Minas Gerais, with participants registered at the Basic Health Units (BHU). Data collection comprised the period between March and May 2017. Ten men undergoing cancer treatment living in the municipality were randomly selected. The number of participants was not previously defined and the field stage was interrupted when the multiple dimensions of the phenomenon were reached and the object of study answered.[8]

Inclusion criteria for the research were: being male, over 18 years old and being on cancer treatment for at least one month. This temporal criterion is important to examine the man during the disease process since, before this period, he would still be under the impact of the disease and would not have experienced the condition of being ill. Exclusion criteria were: presenting neurological or psychic disorders diagnosed by the doctor during consultations at the BHU; have clinical alterations related to the level of consciousness or speech that make the research difficult; man's lack of knowledge about his cancer diagnosis when asked by the researcher about why he is undergoing treatment.

The men were recruited at the BHUs by the nurses themselves from the health units. At first, the researcher investigated which men were diagnosed with cancer followed by the units. Subsequently, the invitation to participate in the study was made by telephone and all agreed to participate. From the consent statement, a more convenient date and place was scheduled for the participants, all choosing their own domicile. There was no withdrawal of participants during the study.

The script for an open interview consisted of the following guiding questions: How did you get your cancer diagnosis? How has it been for you to live with your cancer treatment in your daily life? How have you been taken care of by health professionals? How do you perceive the disease in your life?

The open interviews were conducted after the participants' acceptance by signing the Free and Informed Consent Term (FICT), respecting confidentiality and anonymity. To ensure privacy, questions were conducted in a private place within the household and without the presence of other family members. In order to preserve the general expression of the participants as faithfully as possible, the interviewees' statements, with an average duration of 40 minutes, were individually recorded and later transcribed in full. To protect their anonymity, they were treated by an alphanumeric code, identified by the letter "E", followed by a number that corresponded to the order of the interviews.

The qualitative analysis of the results was done through the content analysis method, following three chronological poles: pre-analysis, material exploration and treatment of results, inference and interpretation. In the pre-analysis, the information was organized, systematizing the initial ideas, later, with the exploration of the material, the categories were defined and, in the treatment of the results, it was sought to identify and interpret the aspects that guided the participants' reports in relation to living with cancer.[9]

This study was approved by the Research Ethics Committee on March 13, 2017, with Opinion No. 1,960,978, CAAE No. 63075116.1.0000.5153, based on ethical and legal principles involving research with human beings, according to Resolution No. 466 of December 12, 2012 of the National Health Council.

Results and discussion

Participants were ten men, ranging in age from 37 to 66 years. Nine of them were between 50 and 66 years old; six were married, three widowed and one single. Of the total, eight lived with people from their own family context and nine declared themselves Catholics. Regarding the type of cancer, four were diagnosed with prostate cancer, which is in line with estimates from the National Cancer Institute José Alencar Gomes da Silva (Inca) that this is one of the most common among men.[1] Three participants were diagnosed with cancer in the gastrointestinal tract (mouth, esophagus and rectum) and the other three, respectively, in the lung, liver and brain.

From the analysis of the statements, the following thematic categories emerged: “The discovery of the diagnosis, the treatment and the changes in daily life: coping and resignification” and “The care offered by the health team”.

Discovery of diagnosis, treatment and changes in daily life: confrontations and resignifications

It was possible to apprehend in the speeches of the participants, that receiving the diagnosis of cancer is impacting and refers to something very serious. At first, it was hard for them to believe the revealed diagnosis and they cried asking God not to die. Having cancer is a harbinger that life is coming to an end.

> *It was the worst news I could get. I confess I didn't believe it when I found out I had cancer. At the time, I was unanswered, just thought I was going to die. I was very scared when I discovered the disease* [...]. (E8)
>
> *No one is prepared to receive such a news, to me it was like receiving a death sentence.* (E10)

These findings corroborate a research conducted at the Radiotherapy outpatient clinic of the Federal University of Pelotas, showing that the diagnosis of cancer was overwhelmingly received and that the patient's first reaction was shock. The disease is shrouded in mystification, beliefs and meanings and is often perceived as a punishment, a death sentence.[10]

Although every human being is sure of death, in the individual and collective perception, the diagnosis of a disease like cancer brings the patient closer to this reality, because it brings the perspective of the finitude of life.[11] This is because, in socio-cognitive forms of thought, cancer is represented as a serious disease, incurable and closely associated with the death sentence, confronting the patient with its limitations and weaknesses.[6]

Men revealed that the diagnosis was lived with fear, added to several feelings such as anguish, indignation, anger, sadness and anger. They saw the situation as a punishment and sought an answer from God.

> *It is a mixture of feeling of fear, sadness, anger* [...]. (E5)

> *At the time, I was afraid to die, I think angry and sad, I never hurt anyone and it happens, I cried a lot and asked God why this was happening to me* [...]. (E6)

The suffering that the individual goes through during the process of illness and cancer treatment implies personal conflicts, often associating cancer with a potentially lethal disease, which makes the discovery of traumatic diagnosis and rehabilitation permeated by the lack of hope of survival with quality, resulting in periods of angst, anxiety, fear and depression. [12-13] Science itself reinforces this notion by classifying cancer as malignant or benign.

In this scenario, it is evident the need to consider, in addition to biological and epidemiological aspects, sociocultural aspects such as the conceptions, beliefs, values, feelings and representations involved in the process of illness and treatment of male cancer, in order to understand the experience of these subjects and of enabling the resignification of their social roles.[6]

They rely on God during treatment because, through religiosity, they seek comfort, strength, meaning for their lives and even the possibility of healing, helping them to endure suffering, pain and symptoms. Changes in religious practices were highlighted as a continuous and growing process.

> [...] *I believe more in God now, this disease brought me closer to him and that was good because it comforted me and gave me the strength to meet this challenge* [...]. (E9)
>
> [...] *The greatest force to deal with the disease comes from God, so what I do to win is pray and ask the creator for a cure.* (E8)

In the most difficult times of cancer, people turn to God as a way to find hope for healing and as a source of support to meet the challenges of treatment and even to comfort themselves in the impossibility of healing.[14] Faith is seen as a contribution, a support that promotes support in the process of cancer acceptance throughout treatment, leading to overcoming in times of crisis and adversity. [10-11,15]

Living with the disease reflected in the way of seeing and thinking about life, so that men began to resignify their priorities, such as the affective ties with the family. They have begun to value the little things in everyday life and believe they have become better people. Attachment to material goods has been replaced by a desire to live a simple and intense life, even with the limitations imposed by illness.

> [...] *I wanted to live to take care of my family.* [...] *now I have a new way of thinking and seeing the world, I value other things that I didn't value so much before.* (E4)
>
> [...] *I see life differently, I value each moment more, my way of being totally changed, arguing for trivial things makes no sense, I stopped being greedy and thinking only about material goods, but now I value the simple, although the disease has limited me in some things, today I have more desire in everything.* (E10)

Other research corroborates these findings by showing that, after the end of treatment, the disease brought a new meaning to life, in which people re-signified their pre-established values before illness. The family is the first social institution of which the individual is part of and it is in this environment that he experiences his first affective relationships, learns to form bonds and internalizes certain values, so, in most cases, is considered the foundation in life of the human being. In this sense, the experience of a serious illness strengthens family relationships and brings people closer.[16]

The men revealed that, in addition to body weakness and pain, they lived with changes in body image from treatment, such as hair loss and weight loss, so that they felt ashamed when leaving home and meet the eyes of other people.

> *After the treatment, I also lost a lot of weight, I lost my hair. At first, I was ashamed to go out on the street like that, because people looked at me with pity, that's too bad.* (E5)
>
> [...] It's the day to day that you really suffer, the treatment has a lot of effects that make us weak. (E8)

The context surrounding the treatment period, the side effects caused by both chemotherapy and radiotherapy and the possible complications that culminate in the need for frequent readmissions, have a direct impact on social, family and work relationships, as well as on the quality of life and on the welfare of the individual.[17] Physical changes resulting from illness and treatment imply changes in self-esteem, generating feelings of pain, suffering, fear, frustration, anguish and despair. Faced with the transformations that permeate the physical, social and emotional aspects, individuals experience some steps until the acceptance of the disease and treatment. In this sense, the confrontation happens gradually and in a singular way.[18]

Men said life changed because they couldn't do the same things as before, such as working and going out to have fun. Limitations, loss of independence and need for treatment are part of everyday life.

> *I did a lot of things, I worked every day, I had to stop working. It made me upset, staying home all day is very bad, it gives the impression that I'm not taking care of my family.* (E9)

> [...] *I suffered from the limitations that the disease brought, I began to feel weak, I did nothing. Know when you feel worthless?* (E10)

Regarding the role played by men in society, it is noted that, culturally, he is responsible for the family, although in the current context, women have an active participation in the financial issue by their insertion in the labor market. Even with this scenario, men still feel compelled to help with expenses and to be the mainstay of the home. Nevertheless, a disease like cancer causes a change in the social roles of the sick and the family.[10]

When the male worker becomes ill, he is confronted with a situation of incapacity to work, even due to the weakness resulting from the illness. A rupture of identity occurs as the constituent elements of what is socially defined and internalized as 'being a man' and being 'a worker' are questioned.[18]

Because of the side effects of treatment, often the autonomy to perform routine activities such as walking and hanging out with friends is impaired.

> [...] *Some days you get a little down* [...] *I can't do what I liked to do because I can fall and get sick and get worse* [...] *you change too much.* (E1)

> [...] *It's so strong that, on the day I do, I can't do anything else, I really enjoy walking, talking to friends on the street and even that I can't do sometimes, it makes me upset.* (E5)

Chemotherapy treatment not only results in changes in appearance, but also directly affects the performance of daily functions that were previously routine. This is because cellular metabolism is altered by the use of drugs, causing apoptosis not only of malignant cells, but directly affecting the body's healthy cells.[19] Thus, side effects can be observed and vary in the degree of aggression, from weakness, fatigue and diarrhea to situations that cause the most damage, such as paralysis of the lower limbs.[20]

Autonomy and independence to perform daily activities provide well-being for people who experience an oncological disease, but they are not always preserved. It is essential that both family members and health services contribute to the permanence of autonomy and the development of new skills, in order to strengthen the patient's self-esteem and stimulate an active life within the possibilities of each individual.[21] Some participants revealed that they resumed activities that were usually performed before their illness, as they provided them with pleasure, such as dancing, fishing, playing cards, and reestablishing contact with friends.

> *When I see the weather is good, I'll take a hake with my brothers* [...] *sometimes we play truco* [...] *we have fun.* (E1)
>
> [...] *I can't stay still* [...] *I go to forró, I have a lot of friendship* [...] *I forget, I don't even remember that I have this problem.* (E3)

Naturally, the individual seeks ways to adjust to the reality and conditions imposed by the disease and, even in the face of a chronic condition, realizes the need to continue his life and resume some daily activities. In rehabilitation, the process of accepting the physical limitations resulting from treatment happens gradually.[13,20-21]

It is noticed that men performed various daily activities, as well as social roles before the onset of the disease. With the discovery and treatment of cancer, the sociocultural context was changed, leading them to redefine the priorities in life. Regarding the role of health professionals regarding the care offered, it is evident that the assistance given to men was essential in the treatment.

The care offered by the health team

Despite the many technological innovations incorporated in caring for people with cancer, participants stressed the importance of bonding, support, acceptance and affection as essential in the treatment.

> [...] *They were amazing and fundamental people for my recovery* [the professionals]*, they helped a lot, gave me support, I knew I could count on them at that moment.* (E4)
>
> *They are great* [...] *consult you, ask how you are, greet in an education, that affection* [...] *we do not see anyone sad, they* [professionals] *make you happy* [...]. (E1)

By guiding care in affection and respect, professionals allow a friendship relationship to be established, so that help the patient in coping with the disease and offer support, encouragement and strength to overcome the situation, as reported by follow:

> [...] *The professionals took good care, until today I get there and the friendship continues, they treat us so well that they even forget that they are sick. Even to give the patient an injection they come in and ask you for permission.* (E2)
>
> *I made many friends with the nurses and the doctors* [...] *they were amazing and fundamental people for my recovery, they helped me a lot, they gave me support, I knew I could count on them.* (E4)
>
> [...] *They took care of me from the surgery until after, when I was recovering* [...] *talking to me* [...] *the whole team motivated me, they didn't*

> *let me down and made me believe that I would win, giving me strength to get out of that situation* [...]. (E6)

It is known that the disease is an unknown path and therefore the dialogue with health professionals, including nurses, contributes to the fight against cancer and the coexistence of the person with the different stages that go through the evolution of the disease. Health professionals should not be restricted to technical knowledge by providing guidance, they must also listen to each other and include attributes present in a friendly relationship, such as hugging, cuddling, playing, smiling together and relaxed conversation. These attributes arising from the human condition itself, emerge as fundamental in care and contribute to the co-responsibility.[18,22]

The strengthening of the bond provides the physical and mental well-being of the sick person and promotes a relationship of help and trust that favors the clarification of doubts, such as limitations and potentialities and adjustments in daily life in the adaptation process. It is believed that acting in this perspective helps the development of strategies for coping with the disease and treatment.[23]

It is noted that the professionals, according to participants' reports, explained about the disease and the limitations imposed by the treatment, as well as about all the procedures to which they would be submitted. Thus, they highlighted that they are aware of the care process.

> [...] *They explain everything that is going on and what they are going to do, they are great.* (E3)

> [...] *I explained things well, since the beginning I discovered the disease, I was always treated very well by all.* (E9)

In this difficult time for the man who experiences an oncological disease, often permeated by depressive symptoms and low adherence to treatment, the presence of professionals with an active listening and an attitude of concern for each other in an authentic way, increases self-esteem, promoting hope and improving coping.[24]

Nursing is recognized for its ability to establish bond and transmit security to the sick person. The support offered allows the individual to feel dignified care with comfort and safety, thus facing the challenges that transcend the biological needs arising from the disease.[25] Being aware of the evolution of the disease and the treatment received allows a greater involvement of men in caring for themselves, assisting in their adherence and co-responsibility.[22]

There is a distancing from primary care in cancer care, since participants did not highlight the performance of professionals inserted in tertiary care. It is essential to sensitize primary care professionals, especially nurses, to offer quality, humanized and integral care, as well as to strengthen the bond with the sick man.

Conclusion

The experience of an oncological disease is permeated by feelings of denial, anger, anguish, sadness and fear. The possibility of death, the threat to their future, the difficulties to adapt to the new lifestyle due to the physical limitations that have implications for social and working life, were evidenced.

It is noted that men sought strategies to overcome limitations such as the support of family, friends and health professionals, as well as religious beliefs, proving to be an important resource for disease control and coping.

These findings have implications for health care, which permeates the entire care network, by giving visibility to issues involving the illness of men due to an oncological cause. It is up to the health professional, including the nurse, to be responsible for establishing a bond, offering support, affection and welcoming the person throughout the course of the disease. Co-responsibility becomes necessary for the individual to take care of himself and seek strategies to face the challenges that emerge from the diagnosis of cancer.

The limitation of the study is related to the investigation of only one reality, portraying the experience of men from the State of Minas Gerais, with the particularities that involve an inner city and cultural issues of that region. In addition, there is a shortage of publications on the theme of cancer in males.

Moreover, new researches are suggested that cover the cultural, social and subjective issues that permeate the man, because it is understood that the involvement of this group in the health field is still low, that is, the search for health resources may be late, directly impacting their quality of life and survival.

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