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ARTIGO ORIGINAL

CANCER REPERCUSSIONS ON LIFE TRAJECTORY AND HEALTH PROMOTION: LOW-INCOME CANCER PATIENTS' PERCEPTIONS

Repercussões do câncer na trajetória de vida e a promoção da saúde: percepções de pacientes oncológicos de baixa renda

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ABSTRACT

Objective: To know low-income patients' perceptions about their trajectory after cancer diagnosis and health promotion actions carried out by them. Methods: This is a descriptive and qualitative study based on conceptual bases of health promotion and quality of life, carried out with low-income cancer patients, over 18 years old, assisted by a Volunteer Center in a municipality in the countryside of Minas Gerais. Recorded semi-structured interviews were used for data collection and the sample was closed using the theoretical saturation technique. Data were analyzed using inductive thematic analysis. Results: From data analysis, two themes emerged: Repercussions of cancer on patients' life trajectory; Health promotion and realignment in ways of living. The reports point out the perceptions about cancer and how it had an impact on ways of living of patients with cancer. Conclusion: Perceptions indicate that the oncological trajectory is hampered by the situation of poverty and that cancer can allow different realignments in patients' life, such as the search for health promotion. In this scenario, health professionals must recognize the potential of health education, seek to strengthen patient role and carry out actions based on interdisciplinary care practice, in which there is integration of all levels of care.

Keywords: Patients; Neoplasms; Poverty; Health Promotion; Quality of Life.

RESUMO

Objetivo: Conhecer as percepções dos pacientes de baixa renda sobre as suas trajetórias após o diagnóstico de câncer e as ações de promoção da saúde realizadas por eles. Métodos: Estudo descritivo com abordagem qualitativa fundamentado em bases conceituais da promoção da saúde e da qualidade de vida, realizado com pacientes oncológicos de baixa renda, maiores de 18 anos, assistidos por um Núcleo de Voluntários de um município do interior de Minas Gerais. Para a coleta de dados foram utilizadas entrevistas semiestruturadas gravadas e o fechamento da amostra deu-se pela técnica da saturação teórica. Os dados foram analisados com a utilização da análise temática indutiva. Resultados: Na análise dos dados, emergiram dois temas: As repercussões do câncer na trajetória de vida do paciente oncológico; A promoção da saúde e o realinhamento nas formas de viver. Os relatos apontam as percepções sobre o câncer e como ele repercutiu no modo de viver do paciente oncológico. Conclusão: As percepções apontam que a trajetória oncológica é prejudicada pela situação de pobreza e que o câncer pode possibilitar diferentes realinhamentos na vida do paciente, como a busca pela promoção da saúde. Nesse cenário, os profissionais de saúde devem reconhecer as potencialidades da educação em saúde, buscar o fortalecimento do protagonismo do paciente e realização de ações pautadas na prática assistencial interdisciplinar, na qual haja a integração de todos os níveis de atenção.

Palavras-chave: Pacientes; Neoplasias; Pobreza; Promoção da Saúde; Qualidade de vida.

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INTRODUCTION

The set of more than 100 diseases that are similar in the fact that there is an uncontrolled growth of cells is called cancer(1). Metastasis is understood as the spread of these cells to other parts of the body, usually through the blood and/or lymphatic stream(1).

It is necessary to recognize that cancer treatment has a strong influence on patients' quality of life(2). It is known that the conception of quality of life is subjective, linked to personal values and influenced by health/disease process repercussions(3). In oncology care, the understanding emerges that treatment factors(4), such as symptoms and the presence of metastasis(5), and socioeconomic conditions strongly contribute to patients' perception of their quality of life(6).

Living with cancer can lead to a loss of vitality, a decrease in physical independence and the full exercise of autonomy and, to some extent, the loss of self, in which there is a level of psychic disorganization that goes beyond the change in self-image, goes through not recognizing oneself in a new body, since it does not respond or correspond to their expectations and life plans(7).

Since lower financial status is associated with a greater risk of deterioration in quality of life(8) and, being in a situation of poverty, vulnerability can intensify this situation and lead to an aggravation of deprivations(9), cancer diagnosis and treatment are considered to have a major impact on the quality of life of a person in poverty. Thus, low-income patients' perceptions on quality of life can take on new contours, considering the situation experienced.

A study identified that, after treatment for cervical cancer, women's quality of life was influenced by the type of treatment and socioeconomic conditions(6). In this scenario, it is important to include quality of life assessment in the treatment process and in the follow-up of these cancer patients(10), since it can contribute to identifying disease repercussions in patients' life and to the elaboration of interventions(6). Moreover, it can favor care planning, rehabilitation and social autonomy of patients with cancer(11).

In this scenario, health promotion appears as a tool linked to quality of life, by asserting the right to health and by seeking to build better conditions and ways for individuals to live(12). Health promotion is a health production strategy that recognizes the complexity of the social determinants involved in the health/disease process, values qualified listening, singularities and people's autonomy, welcoming life stories and ways of living(12). From the perspective of health promotion, it is proposed that care be expanded, operating on health and illness, with actions translated into reducing vulnerabilities and favoring healthy choices(12).

Considering the different facets imbricated in oncology care, multidisciplinary support is needed for patients that promotes quality of life(13). Therefore, identifying patients' perceptions about the disease process and cancer treatment favors understanding disease repercussions on life conditions, which can contribute to constructing behaviors that recognize needs and subjectivities and, thus, allow a more effective humanized care and health promotion. Thus, in this study, the following guiding question was established: what are low-income patients' perceptions about their oncological trajectory and health promotion?

The present study sought to understand low-income patients' perceptions about their trajectories after cancer diagnosis and health promotion actions carried out by them.

METHODS

This is a descriptive and qualitative study based on conceptual bases of health promotion(12) and quality of life(3). The qualitative approach considers the empirical reality, seeks to broaden the view and produce rich information, which favors the understanding of contextualized phenomena(14).

The study was carried out in the municipality of Diamantina, Minas Gerais, Brazil, with low-income cancer patients assisted by a Volunteer Center in this municipality. This Volunteer Center is made up of people from the community itself who seek to contribute to meeting the financial needs of these patients.

Participants aged 18 years or older enrolled in and monitoring by the Volunteer Center were included. Participants who were unable to orally answer the questions asked by the researcher and could not be found at home after three attempts were excluded.

A semi-structured, recorded interview with guiding questions was used to collect qualitative data. This interview script was refined through pilot testing. Data collection, which took place from December 2019 to March 2020, was performed by the first author. The interviews lasted an average of 65 minutes.

After the interviews were carried out, they were transcribed and organized into individual files. At the same time, the process of analyzing the content of each interview was initiated. To close the sample, theoretical saturation was used(15). Theoretical saturation is verified when there is no consistent addition of new types of statements in the process of analyzing qualitative material(15). Therefore, it can signal the achievement of theoretical density(15) and the in-depth understanding of the object studied.

In this study, saturation was visualized in the seventh interview. Thus, seven low-income cancer patients participated in the study, who were named: I1, I2, I3…I7. It is necessary to point out that there was no refusal to participate.

Qualitative data were analyzed using inductive thematic analysis, a method that allows constructing themes from the data collected(16). This analytical process of the qualitative material made it possible to identify two central themes, namely: Repercussions of cancer on patients' life trajectory; Health promotion and realignment in ways of living.

The research was approved by the Research Ethics Committee of the Universidade Federal dos Vales do Jequitinhonha e Mucuri, Opinion 3,229,421 and CAAE (Certificado de Apresentação para Apreciação Ética - Certificate of Presentation for Ethical Consideration) 05010918.9.0000.5108. Research participants signed the Free and Informed Consent Term, printed in two copies.

RESULTS

In a brief characterization, of the seven cancer patients who participated in the research, four are women and three are men aged between 26 and 87 years; most are single, with a family income of one minimum wage and have at least one child.

The time elapsed from cancer diagnosis was from one year and two months to 20 years. Two participants had a recurrence, one when treatment was finished and the other during radiotherapy.

Of the seven research participants, one was diagnosed with laryngeal cancer, one with stomach cancer, one with bowel cancer and four with breast cancer.

Repercussions of cancer on patients' life trajectory

Cancer took on different contours in the reports. Diagnosis and treatment appear as important events for patients, which can have different repercussions on their life trajectory.

After cancer diagnosis, patients can experience difficult moments, often linked to the recognition of the finitude of life:

> In the matter of cancer, you witness a lot of remarkable things. On the negative side, you see a lot of people with a long-life expectancy dying, some going through a lot of difficulties. (I5)

Cancer treatment can generate fears and concerns in patients. An example is mastectomy, in which women may fear the loss of their femininity. However, sometimes treatment can have milder repercussions than the patient expected:

> I was very scared [...] I think I felt a relief when I saw that I hadn't removed the whole breast. I felt relieved. When he [physician] removed the belt, he said that everything went well. I said, "thank God!", and it was really peaceful after surgery. (I3)

Other times, it intensifies some feelings in patients, such as nervousness, presented in the report below:

> Because the person who is sick is already more nervous. You are no longer the same, you no longer have that patience that you used to have.

> You've fallen ill, your patience is already waning, it's almost halved. You talk to a person, and if they say the opposite, you already get nervous. (I6)

Treatment may be associated with stressful events for patients. The experience of alopecia can emerge as a traumatic moment for women:

> On the second day, in the second chemotherapy session, I had to shave all my hair, then it was complicated, very complicated. (I3)

The side effects of cancer treatment can result in discomfort for patients, making it difficult to fulfill basic acts of life such as feeding:

> I was having trouble eating, drinking water. [...] it made me want to vomit, I lost the desire to eat, but I held on, and it went away. (I7)

> Another problem that cancer can cause is changes in the way of living, by making it difficult to return to some activities that are significant for patients such as work:

> It changed that all my life I liked to work, now I'm stuck inside the house. [...] The only thing that bothers me is staying in this whereabouts, I worked all my life, now I have to stand still, I can't even walk properly. (I6)

Health promotion and realignment in ways of living

When faced with cancer diagnosis, participants began the process of questioning the disease, seeking to identify risk and protective factors. There is also the recognition of social determinants of the health/disease process:

> So many things they say, if eating it causes cancer [...] There was one time I cut a tomato, I smelled it, there was a smell of pesticides. They are increasing the dose of pesticides in food. [...] Then you don't eat healthy food, you're just filling your belly. (I6)

> Usually this throat train [laryngeal cancer] is because of the cigarette, but there are times when I keep thinking, there are people who have never smoked, never had any problems and have this problem [cancer]. Sometimes I think it's strange, but the physician said, right, he's experienced [...] (I7)

Thus, cancer diagnosis can usually lead cancer patients to reflect on ways of living. Health professionals can take advantage of this moment to carry out health education, seeking to address vulnerabilities and promote healthy lifestyle habits:

> Something I didn't do, I ate so much junk food, so did my children. Today, no, today, we try to be healthier. [...] I go for a walk, those things. (I3).

> In my farm, the food is only in the dung, the taste is very different. It is important to eat healthy foods. (I6)

> So, I went to see him [clinical oncologist] there now, he told me to stop smoking and come back there in about six months. Cigarette is difficult, but I'm cutting back. Making effort and decreasing. (I7)

Realignments in ways of living resulting from cancer seem to favor social interaction appreciation and acts that previously seemed so simple, such as talking, eating and observing nature:

> Oh, I, thank God, enjoy my life too much! I bless all day, from today [Monday] to Friday I bless. The week goes by, when it's Sunday I go to my girls'

> [daughters'] house. I'm going to Couto, another time I'm going to my girls' house. It's too good, life is good! (I2)
>
> I want to go to the countryside, because there I am distracted, there are birds singing freely in the bush outside, I have my orange plantations, I planted a lot of vegetables there, everything I planted is producing well. (I6)
>
> But, thank God, there were no more serious problems, because I'm talking normally, eating normally, my throat still hurts, but it's fine. (I7)

Rehabilitation processes were envisioned as a possibility to face limitations resulting from treatment:

> Now, I go every week to do physical therapy, because having the surgery under my armpit cut a little bit of the nerve, so I'm losing arm motion. Then, I do physical therapy so I don't lose this arm movement. [...] it relieves me a lot when I do massage and exercises. (I3)

Within the possibilities, autonomy to perform daily activities, such as household chores, also appears to be significant for patients with cancer:

> Nobody does it, I do it myself, I wash the bathroom, I cook, I do everything. When it's the end of the year, when the girls [daughters] want to come spend Christmas here with me, they come and clean the house. But I clean it myself, I do everything (I2)
>
> [...] now, that it has been longer since the surgery, I'm back to cooking. (I3)

In some reports, cancer patients recognize the possibility of coping with and overcoming cancer:

> The way I am do not believe. So, thank God, I'm an example for some people (I3)
>
> I have always been a strong person physically and psychologically. So, I already knew that this [cancer] wasn't going to take me away, you know, kill me. [...] But there are also some good things, a great example is this overcoming that I had [...] (I5)

Some reports point out that, despite facing difficulties arising from cancer, some people are able to positively observe the situation in which they find themselves, which seems to favor feelings of acceptance and satisfaction with life:

> My life is much better now. [...] I'm sick, but I thank Jesus for all the good things I have. [...] Thank God my life is good! (I2)
>
> I learned so much. So, I think today I'm much more mature than before. [...] I am valuing life more today than before. (I3)
>
> I'm afraid, Sir, of fall ill. I ask God not to let this happen to me, but, with us standing up, solving our problems, it's fine. (I7)

DISCUSSION

Cancer diagnosis and treatment stages can bring many questions to patients and their families about the possible causes that led to the disease, triggering an extensive movement to rescue personal and family history, as well as lifestyle habits, seeking to find points that can be characterized as risk factors, which can support healthy changes in lifestyle during treatment and thus positively impact the prognosis.

This is a natural process, which can be important in the elaboration of what happened, correlating it to life history, seeking learning and new ways of seeing and living life that can generate a positive result and make the whole difficult phase of coping not in vain. However, as this process is already expected for the event, it must be monitored by a multidisciplinary team, so as not to generate a cycle of self-blame or blaming patients by their families, which could greatly harm their emotional state.

Based on this concept, health professionals can empathically welcome and guide patients and their support network during the diagnosis and treatment period, seeking to direct them to adequate cognitive and emotional possibilities for coping(17). Through this view, health professionals must understand patients' and their families' beliefs and explain in an understandable way to them what is in fact proven by science and what, in fact, is just someone's opinion. It is also important to alert to the risk of using the internet and social media as a source of information.

Considering the considerations made, the guidelines provided by health professionals are essential in the process of assimilation by patients and family caregivers, in addition to emotional support(18).

Furthermore, the emotional impact generated by challenges experienced in diagnosis and treatment tend to naturally stimulate a movement of looking inward and towards the main values of life, generating deep reflections and a remake or reinvention that can shape a new lifestyle. This being well grounded by the emotional strengthening and resilience that are triggered in the coping phase, which can lead to personal satisfaction and strengthening of personal power.

Resilience in the face of cancer process and treatment can be understood as the ability to deal with adversities with lightness, strength and overcoming, with spirituality being a fundamental axis in this sense, making spiritual care important as part of comprehensive professional care(19).

The period of coping with the entire process becomes an opportune moment for health promotion actions, such as health education practice by the entire multidisciplinary team, both in individual consultations and in group activities. The team must be aware of the relevance of this period for guidelines, which can be reinforced in interprofessional meetings.

Health education actions enhance self-care quality and the management of adverse reactions by patients, especially regarding the adverse effects of chemotherapy, contributing to quality of life during treatment, preventing complications and reducing discomfort and costs with additional treatments(20). Thus, educational interventions based on the construction of skills for self-management contribute to an increase in quality of life and a decrease in anxiety and depression(21).

Furthermore, in educational interventions, it is important to understand both the physical and psychosocial implications(13). In the psychological sphere, it is possible to offer, in addition to quality information, psychological assistance and participation in support groups, for instance(22). In the physical sphere, physical activities can improve not only physical, but also emotional function and contribute to the reduction of symptoms such as nausea, vomiting and constipation(23). Furthermore, health education contributes to individuals and family members seeking healthier habits, optimizing co-responsibility for the outcome of their treatment(24).

However, it is necessary that health education be linked to access to more adequate living conditions so that the guidelines provided are effectively viable in individuals' socioeconomic context(24) and the opposite can become a source of frustration for patients, family members and health professionals alike.

Social withdrawal also represents a difficulty experienced during treatment, which in the present study appeared to be related to interruption in work practices, a situation that should receive a look so that this phase is well managed, seeking other forms of socializing and activities that generate well-being.

The experience of cancer treatment generates biopsychosocial repercussions in patients' life, being essential to encourage communication between patients, family and health team, seeking greater patients' autonomy and active participation(25).

The study showed that cancer treatment, such as mastectomy, has a great impact on patients' life. It is known that the type of surgery affects women's quality of life and body image(26). Moreover, in some narratives, it is noted that the perception of the possibility of proximity to death can bring greater appreciation of life in their daily lives and interpersonal relationships.

Diagnosis is often painful, highlighting feelings of anxiety, fear, and approaching death(25). In the coping process, forces emerge that materialize in changes in the family routine, in activities of daily living, in faith and in the experience of strengthening spirituality(19).

The fear of prognosis and dependence on third-party care was present in the testimonies. This makes clear the importance of patients knowing that health professionals are by their side in this fight, favoring confidence in the good result of therapy and in comprehensive maintenance of quality of life(17).

Therefore, it is important to favor the occurrence of actions based on interdisciplinary care practice, in which there is a focus on each patient's real needs(3), providing comprehensive care(27) that contributed to quality of life(28), thus strengthening patient role(29).

In this scenario, it is believed that the findings of this study can contribute to the expansion of health professionals' view of the biopsychosocial-spiritual needs of patients with cancer, in search of the construction of actions aimed at promoting empowerment and quality of life. Regarding the limitations of this study, as it is a peculiar sample of cancer patients, the results must be assessed carefully.

It is hoped that the present study will encourage further research that addresses the quality of life of patients with cancer in poverty and their caregivers.

CONCLUSION

Participants' perceptions point out that their cancer trajectory is hampered by the situation of poverty and that cancer can allow different realignments in patients' life, such as the search for health promotion. Thus, health professionals working in the oncology area must recognize the potential of health education based on the biopsychosocial-spiritual model, seek to strengthen patient role and carry out actions based on interdisciplinary care practice, in which there is integration of all levels of care.

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