

Networking in the Oncology Field from the Perspective of Users

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O Relacionamento em Redes no Campo Oncológico na Perspectiva dos Usuários Redes en el Campo de la Oncología desde la Perspectiva de los Usuarios

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ABSTRACT

Introduction: The diagnosis and treatment of cancer can cause traumatic consequences, both for patients and their families, which can be minimized through social support. **Objective:** To identify the perceptions of social support of low-income cancer patients. **Method:** Descriptive qualitative approach study based on conceptual aspects of care, carried out with low-income cancer patients assisted by a group of volunteers from a city in the countryside of Minas Gerais, following the criteria of the Consolidated Criteria for Reporting Qualitative Research. For data collection, semi-structured, recorded interviews were used, and the sample was closed using the theoretical saturation technique. The data were analyzed using inductive thematic analysis. **Results:** In the data analysis, three thematic units emerged: interpersonal relationships: the support received from an active collaboration network between people; singularized care as source of support for the health network; and religiosity as a way of coping with difficult situations. These themes portray aspects related to the support network that can contribute for the comprehensive care of the cancer patients, with welcoming and acknowledging needs. **Conclusion:** A solid social support network formed by individuals who play several social roles is perceived as important for better coping with cancer from the perspective of the biopsychosocio-spiritual model.

Key words: Neoplasms; Social Support; Social Conditions.

RESUMO

Introdução: O diagnóstico e o tratamento de câncer podem ocasionar consequências traumáticas, tanto nos pacientes quanto nos seus familiares, que podem ser diminuídas por meio do apoio social. **Objetivo:** Identificar as percepções de apoio social de pacientes oncológicos de baixa renda. **Método:** Estudo descritivo com abordagem qualitativa fundamentado em aspectos conceituais do cuidado, realizado com pacientes oncológicos de baixa renda, assistidos por um núcleo de voluntários de um município do interior de Minas Gerais, seguindo os critérios do *Consolidated Criteria for Reporting Qualitative Research*. Para a coleta de dados, foram utilizadas entrevistas semiestruturadas gravadas, e o fechamento da amostra se deu pela técnica da saturação teórica. Os dados foram analisados com a utilização da análise temática indutiva. **Resultados:** Na análise dos dados, emergiram-se três unidades temáticas: relações interpessoais: o suporte recebido de uma rede de colaboração ativa entre pessoas; o cuidado singularizado como fonte de apoio da rede de saúde; e a religiosidade como forma de enfrentamento de situações difíceis. Esses temas retratam aspectos relacionados à rede de apoio que podem contribuir para o cuidado integral ao paciente oncológico, com acolhimento e reconhecimento de necessidades. **Conclusão:** Uma rede de apoio social sólida e constituída de pessoas que ocupam os mais diversos papéis sociais é percebida como importante para o melhor enfrentamento do câncer na ótica do modelo biopsicossocioespiritual.

Palavras-chave: Neoplasias; Apoio Social; Condições Sociais.

RESUMEN

Introducción: El diagnóstico y el tratamiento del cáncer pueden causar consecuencias traumáticas, tanto para los pacientes como para sus familias, que pueden reducirse mediante el apoyo social. **Objetivo:** Identificar las percepciones de apoyo social de pacientes con cáncer de bajos ingresos. **Método:** Estudio descriptivo con un enfoque cualitativo basado en aspectos conceptuales de la atención, realizado con pacientes con cáncer de bajos ingresos asistidos por un grupo de voluntarios de una ciudad en el interior de Minas Gerais, siguiendo los criterios del *Consolidated Criteria for Reporting Qualitative Research*. Para la recopilación de datos, se utilizaron entrevistas grabadas semiestructuradas y la muestra se cerró utilizando la técnica de saturación teórica. Los datos se analizaron mediante análisis temático inductivo. **Resultados:** En el análisis de los datos surgieron tres unidades temáticas: relaciones interpersonales: el apoyo recibido de una red de colaboración activa entre personas; la atención singularizada como fuente de apoyo a la red de salud; y la religiosidad como forma de afrontar situaciones difíciles. Estos temas representan aspectos relacionados con la red de apoyo que pueden contribuir a la atención integral de pacientes con cáncer, con necesidades acogedoras y de reconocimiento. **Conclusión:** una red sólida de apoyo social compuesta por personas que ocupan los roles sociales más diversos se percibe como importante para enfrentar mejor el cáncer en la perspectiva del modelo biopsicossocio-espiritual.

Palabras clave: Neoplasias; Apoyo Social; Condiciones Sociales.

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INTRODUCTION

Cancer diagnosis can cause doubts and insecurities both in patients and their families¹. Therefore, based in the psychosocial model where health and disease are described as conditions that hold dynamic balance co-determined by interacting biological, psychological, and social factors, it is necessary to address these three variables while caring for these patients².

Social aid also known as social support is defined as interpersonal relationships where persons are available and present to be trusted, show concern with one another, value, communicate, help and aid with the available resources³, with the possibility of involving natural collaborators (the family), informal groups (self-help) and formal and institutionalized as organizations of ill persons⁴. In this context, social support has the potential to moderate the consequences arising from the impact of cancer, specifically concerning the depressive symptoms and quality of life, ensuring better recovery and sustaining its health condition, which can lead to improved quality of life, reclaiming of self-esteem and citizenship⁵.

Thus, social support contributes strongly for the strategies of coping⁶, reduction of the level of psychic suffering^{7,8}, anxiety towards appearance⁹, pain levels and post-treatment inflammation¹⁰ as well. Accordingly, as social support is understood as a remarkable paradigm of promotion and reclaiming of health and diseases prevention, it is necessary to ensure the oncologic patient a dignified care matched to its reality¹¹, promoting more flexible actions, adjusting as much as possible to each patient context¹² and pursuing its protagonism¹³.

As social support can help the process of adaptation and maintenance of quality of life of patients with cancer, it should be assumed the necessity of identifying the format of the support network each patient counts with for care to be planned and implemented with quality¹⁴. The objective of this study in this scenario was to identify low income oncologic patients' perception of social support.

METHOD

Descriptive qualitative approach study based on conceptual aspects of care, understood as dedication to the other, considering its subjectivity¹⁵, carried out in the municipality of Diamantina, Minas Gerais, Brazil, following the criteria of Consolidated Criteria for Reporting Qualitative Research (COREQ)¹⁶.

The participants were low income oncologic patients followed up by a Volunteers Nucleus of the municipality of Diamantina, relying on a team formed by members of the

community who try to provide financial support, mainly to these patients. The inclusion criteria were patients with or older than 18 years, registered and under follow up by this Volunteers Nucleus. The patients who had no ability to respond orally to the investigator questions and/or were not found in their houses after three attempts were excluded.

The refinement of the data collecting instrument elaborated occurred through a pilot-test. Semi-structured, recorded, 40-90 minutes long collecting data interviews conducted by the first author initiated with the research question: "How is your life after cancer diagnosis?". The interviews were conducted at the oncologic patients' homes supported by the Volunteers Nucleus from December 2019 to March 2020.

The sample was closed through the theoretical saturation technique¹⁷. The following procedures were adopted: availability of data records (full transcriptions and recorded interviews); individual analysis of each interview for in-depth comprehension of each record, compilation of the types of themes identified by individual analysis of each investigator through interview; grouping of types of corresponding themes in each category; data coding; migration of the types of themes to a spreadsheet; confirmation of theoretical saturation in each category and visualization of the saturation¹⁷. Based in these procedures, the theoretical saturation was achieved in the seventh interview. Nobody declined to join the study, seven low-income oncologic patients were assigned the codes E1, E2, E3..., E7.

Data analysis followed the thematic inductive analysis, a coding process based on the collected qualitative data¹⁸. This process identified tree thematic units: interpersonal relations consisting in the support received from active collaboration network among persons; individualized care as support source of the health network, and religiosity as way of coping with tough situations. No software was utilized to manage the collected data.

The Institutional Review Board of the Federal University of Vales do Jequitinhonha and Mucuri approved the study, approval report number 3.229.421.

RESULTS

Upon a brief characterization of the seven study participants, four were females and three males aged from 26 to 87 years old, most catholic, single, with sons and family income of one minimum wage.

The time passed after the diagnosis of cancer was of one year and two months to 20 years, two participants relapsed, one when the oncologic treatment ended and other during radiotherapy. Most of them was treated in Belo Horizonte,

with support from the Volunteers Nucleus for more than one year. Of the study participants, four were diagnosed with breast cancer, one with intestine cancer, one with stomach cancer and one with larynx cancer.

INTERPERSONAL RELATIONS: THE SUPPORT RECEIVED FROM AN ACTIVE COLLABORATION NETWORK AMONG PERSONS

Family is one of the main sources of support perceived by the interviewees. They report the importance of the presence, be with them to fight against cancer:

Yes, he [the nephew] gives me, it is the only that gives me confidence. He said: “aunt, I will pick you up [...] we are going for a walk [...]”. Once, we were in a big party in the city [the city where the nephew lives], he was with me and said: “aunt, everybody, listen up, I will never ever leave you [...]”. And he never did, thank God! (E1).

Of the own family, some relatives, siblings, you see? Because they had their own lives, a tough routine, I believed they wouldn't, they could not be so present, but they were there. This part of the support is quite important in itself (E5).

The presence of any relative to accompany the patient during the oncologic treatment and financial support, needed in certain conditions, were highlighted in the narratives:

My daughter comes with me, that one you see in the photo, look [shows a picture], she is with me all the time, every month when I go (E2).

And there is my nephew from Belo Horizonte [...], he helped me so much (E7).

Friends were another support source the interviewees mentioned. This support, like the family's, happens in different moments of the diagnosis and the oncologic treatment and it is expressed as an amiable presence as reported below:

Had a friend with me, the first time [at the diagnosis of cancer]. It was very important, it means we are not alone, isn't it? There is always someone. [...] My friends helped me, a friend did my haircut (E3).

The girls [friends] all of them come over, not so often because they live far away, [...] but when they come, they show up to see me (E1).

The demonstration of support can occur otherwise. Quite often, friends notice the person is living tough moments as coping with cancer and try to aid and help as the narratives show:

I have many friends [...]. Thank God, they give me a lot of stuff. Got money from São Paulo, a friend

sent me these bowls, she gave me. She sends many nice things from São Paulo. She sends cash, tells me to buy things ... (E2).

[...] many persons canvass on my behalf, they helped me very much! I think the support was critical and still is. To this date, they continue helping me (E3). Sometimes, they bring me some sweet pastry, cookies, they are with me during the treatment (E6).

Neighbors and co-workers are important persons because they are attentive to the different necessities of the oncologic patient. It can be financially, help with the daily tasks and being present during hard times as the narratives made clear:

I earn one minimum-wage, but it covers my expenses because the neighbors help, I usually find some banana at my window. Once, I had no cash to buy bread, make coffee and said: “My God, what am I going to eat?” When I looked under the door, there were ten Reais. I said: “Ok, this is great!” Another day, I found five Reais (E1).

They [neighbors] help me very much. Some home tasks I can't do because of the arm, they come over and do for me, cook the meals, clean up the house, laundry (E3).

In the shop too, during the treatment, I was in leave of absence, the colleagues [co-workers] were there for me. It is very important, it is swell (E5).

The role played by the Volunteers Nucleus of the municipality of Diamantina appears in the interviewees narratives as source of financial and emotional support:

That lady N. [leader of the Nucleus] has been helping. I want to meet her, still wasn't introduced. She has a good heart (E7).

I showed her the results of the biopsy, then she [leader of the Nucleus] told me: “whatever we can do, we will”. And they really did [Laughs] When I must pay for a test, she [leader of the Nucleus] helps me because I'm not earning anything from INSS. [...] They help me beyond I ever expected, financially, two Volunteers visit me at my home. We talk through WhatsApp too (E3).

As noticed in this thematic unit, the help granted from a supporting network formed by family, friends, neighbors, co-workers, and community can favor feelings of acceptance and welcoming.

THE SINGULARIZED CARE AS SUPPORTING SOURCE OF THE HEALTH NETWORK

The experiences lived in different instances of the health care network can be understood as moments of

support to the oncologic patient. There were narratives of satisfaction with the hospital care received:

For me, whatever, in both [hospitals] I was well cared can't complain of either one [...] They made me feel well (E6).

It is great! They hug you, really, you know? They ... I can't complain of anything, I'm not the best person to say anything. [Laughs] I love it, wow, I was bedazzled. [...] The staff, everyone, treats nobody indifferently, all of them, everyone is treated equally, the reception, the cleaning team, nurses. I like it there (E3).

The importance of the amiable approach of the health professionals acknowledging the biopsychosocial necessities of the oncologic patient appeared in the narratives:

Very good, nice contact, huge concern from them [the doctors] with us. They take it all, the body, and the mind. They care about this too. They target the person's psychology (E5).

One of the nurses in Montes Claros is a dear friend today. He and another female nurse, also from there [hospital], they continue helping me to this date (E3).

This support emerges also in the relation doctor-patient, with active listening, accessible language and empathy as the narratives point out:

I tell the doctor everything and he talks with me there, he gives me guidelines (E2).

But she [the doctor] calmed me down in both times, thank God! (E3).

I said, "I feel this", and he [the doctor] said: "this is normal, the treatment does this". Because, sometimes, you start feeling something you ever felt before, than you ask, and he explains (E6).

During cancer treatment, further to health care professionals, the patient can meet persons who are living similar situations, which creates an affective bond. This can occur, for instance, in the supporting entities as an interviewee stated:

Wow, it was great! [Laughs] It was a hubbub. [Laughs] Just fine, like family, no fights, at all. Everybody teasing at one other, there was a cafeteria, all together to eat. In the evenings, we played cards, watched TV, went to the movies, it was near the mall. It was great! [Laughs] It was wonderful getting along with them (E3).

RELIGIOSITY AS A WAY OF COPING WITH TOUGH SITUATIONS

Religiosity for many is a source of support during tough moments faced during oncologic treatment:

It boosts you up. The Eternal Divine Father and Our Lady Aparecida helped me to face cancer. Jesus is there in my room, a painting this big, look [shows the size] (E2).

A few of them talk about the strengthening of the relation with the divinity they believe:

"On the contrary, I have more faith in God than before" (E7); the trust in the divinity: "We, without God, we don't live, do we?" (E4); and the gratitude for the life you have: "No, I don't go to church, I pray a lot, I pray all the time, every night, gratefulness for living here, for my neighbors who help me, for everyone who support me, before sleeping, I pray for all of them" (E1).

So, bear upon every kind of support can emerge as an important protection factor to cope with cancer:

Well, it was essential. I think it was essential, you see?! Essential, essential, the support I've got. Because, if you don't have it, you have no reason to move on (E3).

DISCUSSION

Aware that social support emerges from formal social relations and roles played in the society and by the social informal relations where the connection happens because of kinship or affective involvement¹⁹, it is perceived that social relations exist in persons' life and can change through the years²⁰.

Thus, family become a pivotal source of support and ends up needing a support network also to play this role, having in mind that the family most involved in this process tends to seek emotional balance themselves and in their daily activities. Quite often, this situation demands better timing and financial organization creating a phase of great demand upon the family so any type of support to the patient means a support to the family and vice-versa. Therefore, the support network with neighbors, friends and co-workers is utterly relevant and favors substantially the process of adaptability to the phase of coping with the diagnosis and treatment as the results of this study showed which can impact the prognosis positively.

The social support network must be recognized as part of the communitarian context with potential to influence

the functionality and organization within the families being highly beneficial the formation and/or fostering of a culture of cooperation among the families and the community that can protect its members, especially relevant in situations of more social vulnerability²⁰.

In the contemporary world, where in general persons tend to be overwhelmed with activities and reduced time to offer support, neighbors play a relevant role for being closer and prompted to identify a necessity and within the person physical reach and the family who asks for support. Neighbors can represent an important mediation between the patient and the family or between the patient and the health service, facilitating the identification of a problem earlier and referral to someone or any institution that is able to meet this necessity. It is beneficial that this is encouraged within the community environment as schools, churches, and health services, especially in the Strategy Family Health (ESF), having the bond with the community as one of its core pillars.

Neighbors are important players of the social support network promoting improvement of the well-being, safety, and quality of life this network is able to grant to the individuals who have the opportunity of being benefitted, favoring feelings of belonging and trust²¹.

The ESF proposes, organizes and integrates health actions within a defined territory from a family-focused care considering its social and physical surroundings, ensuring extended understanding of the process health-disease and possibilities of interventions and interactions^{21,22}. In addition, when health teams come closer to the families, dialogue and trust processes may be developed to favor the expression of concerns and doubts clarification²³.

When the oncologic patient belongs to an impoverished family, social support is still more relevant²⁴. Within this perspective, the support offered by volunteers and social organs emerges, which, with empathy, endeavor to help anyone experiencing a discouraging situation. Recognition and dignification of the work and worth of learning surfacing from this practice are of essence, making more visible this activity as an integral and important part of the network²⁵.

Some narratives revealed, it was relevant to notice, the alternatives the network support found to meet some material demands, common in low income settings, as leaving some food or cash in the window or under the door. These examples may show the relation between the increase of the social support received and the improvement of the social relations, self-esteem, happiness to live the life and feeling of community²⁶.

The accounts showed this support was key in some moments. These findings indicate that it could be

important to encourage the community to find alternative and creative ways to provide support for those who need. This could be encouraged in several manners in the community through social media, radios, newspapers, churches, and billboards in primary and secondary care health units, among other.

The co-workers were also valuable in the support network. Sometimes it may appear as financial support²⁷. Another impressive aspect shown is the relevance of this support for the patients' family that need to take leave of absence for a period to follow up and this will be easier when they are understood, helped and sustained in their work environment. If the family and caretakers experience better emotional conditions in this stage, the family is able to offer better care while coping with the disease, improved well-being and quality of life of the patient and good treatment outcomes.

It is known that social support in the job grants higher levels of satisfaction in fulfilling their tasks²⁸. In addition, it is related to the cooperative interaction among colleagues and their superiors, it contributes to reduce the wearing of the worker and health risks among other important benefits for the human being living in society. Therefore, the elements connected to social support should be investigated and recognized, valued, and promoted, pursuing human and productive interactions in the working environment²⁹.

The formal support from health professionals, especially concerning the quality of the communication during the interaction, humanized attention, and full holistic care not focused only in the disease, signs and symptoms is remarkable. Nevertheless, health professionals should attempt to provide individualized care that meets the necessities of the oncologic patient³⁰.

Furthermore, the advocacy of the patient can be practiced, understood as its defense by the health professional, a process permeated by empathy, prioritization of health and protection of the patient rights³¹.

In the perspective of full and humanized attention as essential component of the support network, it is important to focus the vision to the processes of work, valuing the wisdom and contribution of professionals and users in the construction of this process, acknowledging the worth of team work and intersectoral approach with insertion in network³².

To live the spirituality has proven to be an essential as well as protective and strengthening element, contributing for better levels of well-being, trust, and courage. Spirituality is understood as a questioning of the meaning of living and be in the world, where it is not needed to have a God or religiosity as a belief in something divine and practices related to a doctrine whose base is faith³³.

Spirituality functions as a protective factor against psychic symptoms resulting from a disease³⁴. Nevertheless, for being an influencer of the process health-disease, spirituality should be seen within a holist approach in caring for the individual so the discussion of this element needs to be included in the formation of health professionals which can contribute for the development of future specialists for them to be more receptive and crafted to welcome, understand and support the individuals in their necessities³⁵.

In this study, based in the scenario presented, it is considered that a support network with elevated level of effectiveness is an important differential to improve the quality of life³⁶ and to pursue more appropriate coping strategies³⁷ for difficulties along the course of life, especially in situations of vulnerability. For this, mutual interaction, recognition and strengthening among the network support focus, collective appreciation and feedback inside the network are important.

CONCLUSION

It is possible to notice through this study the importance of a solid social network formed by persons who play several social roles for better coping with cancer in the perspective of the biopsychosocialspiritual model.

In addition, it is understood the importance of a health professional who is not only able to treat the disease, but also the patient with its singularities. Therefore, the health professional needs to provide more humanized and committed care, to listen actively, have empathy and respect.

Grounded in this conception, it is believed that during the health graduation courses it is necessary to develop a wider vision of the patient, the full care, how the communication is made that ensures an active dialogue to enable a better understanding between the health professional and the patient and the practice of health education and advocacy of the patient.

Finally, it is expected that this study encourages and contributes with new surveys identifying and evaluating the social network support of the oncologic patients in other contexts. Although the material produced in the current study is relevant for health students and professionals, they need to be evaluated cautiously because they involve a peculiar sample of oncologic patients.

CONTRIBUTIONS

William Messias Silva Santos and Nadia Veronica Halboth contributed substantially for the conception and study design, collection, analysis and interpretation

of the data and wording of the article. Jaqueline Silva Santos and Raquel Dully Andrade contributed substantially for the wording and critical review. All the authors approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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