

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

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Highlights: (1) The family is the central figure in the support network for young women with cancer. (2) Religious/spiritual manifestations are strengthened as part of the support network. (3) The humanized work of nursing professionals enables bonds of trust.

PRE-PROOF

(as accepted)

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SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

ABSTRACT

The aim of this study was to get to know the support network of young women undergoing cancer treatment. This is a qualitative, descriptive study carried out using semi-structured interviews mediated by the dynamics of creativity and sensitivity. Twenty young women undergoing cancer treatment took part. The settings were the chemotherapy and radiotherapy outpatient clinics of a university hospital in Rio Grande do Sul. Inductive Thematic Analysis was used to analyze the data, and the National Humanization Policy was used as the theoretical framework. Most of the women were experiencing cancer for the first time and were undergoing cancer treatment for curative purposes. The analysis of the interviews emerged in two thematic categories: “Nursing as a reference in care”; and “The support network in the course of cancer therapy”. The support network was characterized as an important coping tool, consisting mainly of family, faith and religiosity, friends, and the healthcare team, with emphasis on the professional nurse.

Keywords: Young adult; Neoplasms; Therapy; Social support; Nursing.

INTRODUCTION

Cancer is considered to be one of the main public health problems in the world, with an increasing incidence and mortality rate in people up to the age of 70. Although its incidence is higher in developed countries, mortality from the disease is higher in poor or developing countries, due to the difficulties in accessing early screening, diagnosis and treatment¹. Cancer is the name given to malignant neoplasms that result from abnormal cell growth, causing uncontrollable and aggressive multiplication, with the potential to spread rapidly to other regions of the human body, forming tumors².

Worldwide, the most recent estimates, which correspond to 2018, show that there were 18 million new cases of cancer and 9.6 million deaths, with the highest incidence of lung cancer with 2.1 million cases in both sexes, followed by breast cancer with 2.1 million cases, colon and rectum cancer with 1.8 million and prostate cancer with 1.3 million cases. In the female population, the highest incidence is breast, colon and rectum, lung and cervix cancer; and in the male population, lung, prostate, colon and rectum, stomach and liver cancer are estimated to

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

predominate³. In Brazil, 704,000 new cases of cancer are estimated for each year of the three-year period 2023-2025, with breast cancer being the most common among women⁴. Breast cancer is the most commonly diagnosed cancer and is also the leading cause of death among women, followed by colorectal cancer, lung cancer and cervical cancer³.

Despite the advances made in terms of early diagnosis, cancer treatment and, consequently, greater survival for these individuals, their treatment is marked by a reduction in daily activities, bodily transformations, limitations, mutilating surgeries and other factors that directly affect the self-esteem of those living with the disease⁵. Together with the discovery, there are changes in their behavior, from the biological, physical, psychological and social spheres, which reflect feelings of anguish, fear and suffering, as well as uncertainty in the face of the pathology that is significantly associated with finitude⁶.

The life stage of young adults is usually permeated by characteristics related to great vitality and appreciation of individuality, in which the results of their actions are often desired immediately³. However, despite the fact that young adulthood is characterized by significant work functionality, a good disposition and adequate health conditions, this population has shown significant rates of illness and death, mainly related to the onset of cancer.

A cross-sectional study of 12,689 cases of breast cancer in young Brazilian women found that this group has more advanced disease and a worse therapeutic response when compared to women over the age of 35⁷. In this sense, cancer patients go through intense processes of personal, emotional, social and collective change, reflecting in the weakening of their support systems, especially when it comes to people with close emotional ties⁸.

In this context, it is up to the health professional to plan care that goes beyond the issues of the disease and considers the social representations that cancer brings to these people's lives, especially when it comes to psychosocial aspects⁹. Thus, the role of the nursing professional is emphasized, in view of their responsibility for planning care, since by implementing individualized and humanized care they occupy an important space in the lives of these people, becoming part of the support system for the patient and those close to them¹⁰.

In view of this, the National Humanization Policy (NHP) of 2003 stands out, which proposes to cross-cut the different actions and management bodies of the SUS. As principles that structure the policy, the NHP includes transversality, inseparability between care and management, protagonism, co-responsibility and autonomy of individuals and groups¹¹. It also

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

presents guidelines aimed at welcoming users, expanded clinical care, co-management, defending user rights, fostering groups, collectives and networks¹¹. The NHP, in turn, must be evidenced in the scenario of cancer treatment experienced by young women, as well as their social relationships listed as a support network, thus being the theoretical framework that underpinned this study.

This study is therefore justified by the need to understand the space occupied by things, people, beliefs and/or everything that young women with cancer and undergoing cancer treatment consider to be part of their support network. The establishment of a support network helps in the process of coping with cancer therapy, in a way that encompasses the set of various significant bonds formed through the relationships that each person cultivates, from integration with closer people such as family and friends, to more formal or sporadic relationships such as work colleagues, neighbors, health professionals and institutions frequented^{12,13}. Social support is characterized as the factor that develops the process of interaction between people or institutions that make up a network, through which bonds of friendship and trust are established, providing emotional, material and affective help and providing reciprocal relationships and important aspects for the prevention and maintenance of health¹⁴.

There are several forms of support network that can be strengthened and built during the cancer treatment process, one of which is the act of prayer, which often helps women, for example, to overcome the fear of obstacles and to receive a cure, because they can remain calmer to better understand the mechanisms of the disease¹⁵. In addition, attachment to faith provides the hope that supports young women when they are overwhelmed by the anguish of the premature possibility of the end of their lives.

These coping strategies can mitigate the stress triggered by cancer treatment, giving way to thoughts of hope and alternatives that make it possible to be comfortable with the new reality, as well as helping to learn new skills and behaviors¹⁶.

In addition, it has been observed that cancer diagnoses in young women are on the rise in various regions, with a particular emphasis on some specific types of cancer, such as breast, cervical, thyroid and melanoma, making it necessary to identify signs and symptoms earlier and earlier in order to improve health outcomes and treatment options. Research carried out in the United States, for example, pointed to a 19.4% increase in breast cancer diagnoses between 2010 and 2019 among American women aged 30 to 39, and a 5.3% increase among women

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

aged 20 to 29, reflecting a global reality regarding the incidence of cancer diagnoses in young people¹⁷. As this is an economically active age group, cancer diagnoses tend to be made late in young women's lives, which can compromise the pathology's prognosis. Cancer treatments can sometimes directly interfere with women's reproductive capacity and fertility, as well as affecting the social and emotional spheres of this target group, as it encompasses the period of building, for example, a professional career, social growth and development and emotional relationships¹⁸.

Given these considerations, this study was based on the following research question: how is the support network of young women undergoing cancer treatment characterized? In order to answer this question, the aim was to find out about the support networks of young women undergoing cancer treatment.

METHODOLOGY

This is a qualitative, descriptive study¹⁹. The criteria of the COREQ (Consolidated criteria for reporting qualitative research) checklist were followed when conducting the research²⁰. The settings of the study were the Chemotherapy Outpatient Clinic and the Radiotherapy Outpatient Clinic, which are part of the Hemato-Oncology Sector at the University Hospital of Santa Maria (HUSM), RS, Brazil.

The participants in the study were 20 young women with cancer who were undergoing cancer treatment at the above-mentioned units. There were 24 attempts to attract participants to the study, but four women refused. A pilot test was carried out in order to improve the data collection instrument. The criterion for closing the interviews was that the data collected was sufficient in quantity and intensity to respond to the research objective and the many dimensions of the phenomenon under study¹⁹.

With regard to the eligibility criteria, in the face-to-face data collection modality, young women aged between 20 and 40 diagnosed with cancer and undergoing cancer treatment at the aforementioned institution were included. In the virtual modality, we included young women aged between 20 and 40, diagnosed with cancer, undergoing cancer treatment at the aforementioned institution and who previously had electronic devices such as cell phones and/or computers so that they could participate in the study. Those who had clinical conditions that would prevent them from taking part in the study, making it difficult to communicate in

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

the interview, were excluded on the basis of information previously provided by the health team. It should be noted that no eligibility criteria were established as to the type of treatment; any type was included in order to include the largest number of participants undergoing cancer treatment.

To select the participants, we used data from the medical records of the Chemotherapy Outpatient Unit and the Radiotherapy Outpatient Unit, which corresponded to the following variables: gender, age and whether or not they were currently undergoing cancer treatment; after this analysis, we applied the inclusion criteria. Based on the variables listed, it was possible to organize the group of probable participants according to the eligibility criteria of this study. The participants were then randomly selected through individual invitations. This was done while the women were waiting for their appointments and, depending on the participant's availability, the interview was conducted in person or virtually.

For data collection, the semi-structured interview technique and the Creativity and Sensitivity Dynamic (DCS), known as the Talking Map (MP), were used. For this construction, some open-ended questions were asked, such as “What people, objects, things or places do you consider to be your support network for coping with the process of undergoing cancer treatment?; What strategies/resources do you use to cope with these difficulties?; How do you feel about undergoing this treatment?; How is the care provided by the nursing team?, among others”. Regarding the form of data collection, face-to-face and remote possibilities were chosen, taking into account the participant's availability and preference.

Data collection took place from July to September 2021, lasting an average of one hour each. During the collection period, the Covid-19 pandemic was being experienced, which required adjustments to capture the study participants. Thus, 17 interviews took place face-to-face, in spaces made available by the staff of the units and taking into account the absence of noise or disturbances that would interfere with the privacy of the participants. To this end, the biosafety and SARS-CoV-2 prevention measures were followed, as established by the Biosafety Manual for the UFSM Academic Community²¹.

In the remote data collection modality, three online interviews were carried out via audio and video calls through the WhatsApp application and the institutional Google Meet, depending on the participant's preference and accessibility. For the development of the Talking Map, the materials (paper, colored pencils and others) were made available by the researcher in the

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

services for the women who accepted the invitation, so that they developed, recorded and sent the photograph via WhatsApp of the artistic production resulting from the dynamics.

The information from this research was audio-recorded, with permission, using a digital recorder and then transcribed in full and submitted to Inductive Thematic Content Analysis, which consists of six stages²²: 1) familiarization with the data; 2) generation of codes; 3) search for themes; 4) review of themes; 5) definition and naming of themes; 6) production of the report. In order to identify, analyze and report on themes from the data, the strategy of chromatically marking the statements was used to list the generation of similar codes, in order to organize and describe them in detail.

This study followed the ethical aspects of research with human beings, in accordance with Resolution No. 466/2012 of the National Health Council, which deals with the Guidelines and Regulatory Standards for Research Involving Human Beings²³, and respected Resolution No. 510/2016, which sets out the standards applicable to research in the Humanities and Social Sciences²⁴. The study was approved by the Ethics Committee of the aforementioned educational institution, which gave a favorable opinion under report no. 5.131.947 and CAAE no. 47529521.4.0000.5346. Prior to the interview and after clarifying the objectives and method of the proposed work, the participants signed a Free and Informed Consent Form. As a guarantee of the participants' anonymity, the young women were identified by the letter "M", referring to Woman, followed by an Arabic numeral according to the order of the interviews (M01...M10...M20).

RESULTS

The study participants were 20 young women aged between 20 and 40. In terms of schooling, five had completed high school, four had a technical degree, four had incomplete high school, three had incomplete higher education, two had completed higher education and two had incomplete primary education. With regard to monthly income, five reported a monthly income of up to one minimum wage, another five between two and three minimum wages, four participants reported an income of more than four minimum wages, three participants between three and four minimum wages and another three reported a monthly income of between one and two minimum wages. With regard to marital status, 10 were married, nine were single and one was widowed. Six of them reported having no children, another six had one child each, five

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

participants had two children and another three participants had three children each. With regard to diagnoses, breast cancer predominated in 12 participants and Hodgkin's lymphoma in three participants, followed by diagnoses such as cervical cancer in two participants, non-Hodgkin's lymphoma in one participant, adrenal carcinoma in another participant and Langerhans cell histiocytosis in the perineum/vulva in one participant. Of these, 15 were experiencing cancer for the first time, while another five were experiencing a recurrence of the disease. With regard to the length of time they had been undergoing their current treatment, 13 participants reported that they had been undergoing cancer treatment for approximately one year. With regard to the therapeutic purpose, 13 were undergoing curative treatment, six maintenance treatment and one palliative treatment.

The analysis of the interviews from the perspective of the National Humanization Policy resulted in the construction of two thematic categories: Nursing as a reference in care and The support network in the journey of cancer therapy.

Nursing as a reference in care

This category presents aspects that place nursing care as fundamental and central during the cancer treatment carried out by young women. The statements express how the nurses provide care based on affectionate actions, showing that they provide humanized care and respect the situation experienced by the study participants.

I've always been very well looked after here, they've always been very attentive. Exceptional. So, I'm delighted with this humanized care because you think of humanized care, you think of this heart thing, and how is it that with this involvement, with this affection, you can separate it? And they manage to separate without being cold and still show that affection, that care. (M10)

The [nursing] girls were very attentive to me. I was always treated very well. Even after we had the conversation with the medical board, the head nurse, I thought she'd never remember and the other day she came to ask me how I was. It's such a small thing to other people, but it makes such a difference to us at these times. And it's good when we feel welcomed because we're already fragile, we're already in such a bad phase of life, and you still find bad people there, it's hard. (M14)

I like them all. They're very good for us [...] the nurses are always looking after us, you know, that's very good. Because it helps you get through this phase, because you see that they are interested in you, in your case. I feel safe and welcomed here, that's for sure. (M16)

I felt well prepared, very well looked after by the nursing staff. Their treatment here is spectacular. The nursing staff are wonderful, they're people who are totally qualified to deal with us. People in our case, who are psychologically shaken, they are wonderful, they make a lot of difference, a lot of difference. I feel very welcome. (M19)

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

I felt safe, I felt good [...] if I could give back the love they have for what they do and for us [...] just sometimes getting a smile, because sometimes you're not feeling well, sometimes even the person who's doing it isn't having a good day, but they're there with a smile on their face, with a conversation, you know. That makes a difference to us, that was everything to me. (M20)

They are very humane people, they are an example for any type of hospital. I think the people who are studying for their degree should come here to do their internships, to see how humane it is here. How they give importance to everything we say, I was treated very well. The nursing girls who were with me, wow, they're a show. I think they're professionals who are here with their hearts in their hearts. (M05)

Another aspect emphasized was the professionals' concern to answer the women's questions, paying attention to their effective understanding in order to better manage their treatment, so as to minimize possible maladjustments that could harm and/or delay their therapy.

The girls are lovely, I love everyone here, I've always been very well looked after here, I have nothing negative to say. I've always received a lot of guidance, any questions I had I asked, if it hurt I called the nurses. (M01)

The nurses really make everything happen in the hospital. They were everything, in chemotherapy I knew them all, some even changed, but most of them are still there. I'd get sick and they'd help me a lot. They talked to me a lot. The nurses talked to me more than the doctors, you know? that's why I'm saying that the nurses are the ones who make everything happen. I really feel that energy. (M02)

The nurses were always incredible, they always asked "do you have any questions? do you need anything?". They were all very kind, you know, even when I was hospitalized. Now, when I came for chemotherapy, the girls remembered me and I spent two years out there, you know, I can't explain it, they're very loving. (M04)

The support and the way they welcomed me here, the affection, attention, dedication of the staff, I felt super safe, I have nothing to complain about. I love the girls to this day. I received a lot of guidance, both for myself and for my mother. (M06)

The nursing staff are exceptional. I received a lot of guidance, the girls are very delicate, very caring, you know, I don't have any complaints [...] it made a difference in the treatment, because sometimes we get down here and we go in and they're waiting for us with a big smile. It lifts your spirits, they're very, very good. (M07)

The women emphasize that care that goes beyond technical-scientific knowledge and also includes a humanized welcome and care makes a difference for those who experience cancer treatment.

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

The support network during cancer therapy

In this category, we present the speeches referring to the people, places, institutions, beliefs and other factors that served as support and made up the support network for young women undergoing cancer treatment. In order to give density to the questions about the support network, the participants illustrated their answers in the form of a Talking Map.

The main mentions of a support network were family, religious institutions, faith as a whole and friends. In this sense, they report the search for religiosity as an important source of support, outlined by the process of accepting the diagnosis and faith as a driving force for understanding and carrying out a treatment that is less impactful. The family nucleus, made up of the most diverse members, was reflected in a support network based on bonds, affection and concern, making the women feel grateful and secure because they were not going through this cancer process alone. Some of the participants mentioned friendships as their main support factor, listing the contact and help of friends as indispensable in the dynamics of their treatment, ratified by their interaction during the course of these women's pathologies.

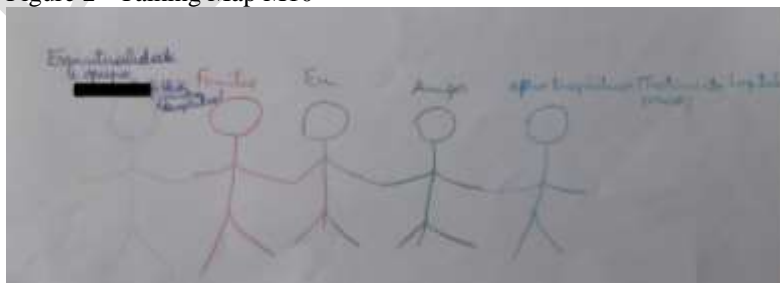
Figure 1 - Talking Map M07.



Source: research data.

I received support from my mother, my father, an aunt and an uncle, so the family was very welcoming. My sisters, thanks to them too. And my husband is very supportive too." (M07)

Figure 2 - Talking Map M10



Source: survey data.

Everyone, even wanting to be more present, to give support and everything. Family comes more directly because they experience the process more closely, and friends. And this question of these searches for well-being, through the group, the question of therapeutic support and the actual care of the girls here.

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

And I put together the question of psychology, which is not of the same holistic line [...] and indirectly it's a current. Maybe this one doesn't know this one, who doesn't know this one, who doesn't know this one, but indirectly they are connected. (M10)

Figure 3 - Talking Map M13



Source: survey data.

I had my mother who looked after me and stayed with me, because my husband worked, my daughter studies abroad, so so that I wouldn't be too alone, she would come [...] my religion, my spirituality, my family [...] the hospital, because it's the place where I experienced all this, where I was well looked after, welcomed. And finally, I'm going to mention the integrative therapies I'm doing. (M13)

Figure 4 - Talking Map M14



Source: survey data.

We had a lot of help from my parents, from my husband's family, my niece who lives next door, my other sister-in-law [...] but I also had a lot of support from my husband, that was the main thing, from the beginning when I found out, it was from him and my children [...] I have a lot of faith in God and in Our Lady and I had more faith [...] The treatment, the way they [nurses] treat us, the affection. (M14)

It is worth noting that the women also listed the search for alternative therapies, participation in groups (in person and online) and the health care provided by the professionals at the hospital where the study was carried out as points of support.

DISCUSSION

The transformation in the life of a woman with cancer is more pronounced when it proves to be a restriction on her social life, such as the reversal of roles, in which the person who used to take care of everyone around her now needs to be taken care of²⁵. And as a consequence of the illness, this woman quits her job, limits her domestic and social activities, contributing to the development of feelings such as depression and social isolation²⁵.

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

The support provided by family and friends is essential in overcoming fear, anxiety and depression, and can provide women with optional ways of living, even with limitations, in order to contribute to the fight against the disease, making up for shortcomings and helping women achieve greater acceptance and behavioral stability²⁶. Family is the main source of support for women during cancer treatment, as they can offer direct care or indirect support. Thus, these individuals not only provide emotional comfort to the woman, but also help her in her daily activities, taking on her chores around the house and caring for the children, while the woman is physically and psychologically debilitated²⁶.

When illness occurs in the life of the family, it is necessary to review its structure and functioning in order to build a place for the illness in their lives. In this context, new demands arise and new tasks are added to the daily lives of the family and the sick person²⁶. At the same time as one of the members falls ill, there is a necessary change in routines so that functional roles can be reallocated, with reorganization as the focus of the well-being of the patient undergoing cancer treatment. In view of this, during illness, the PNH states that an ever-present question is whether it is possible to “go back”, to return to the way things were, bearing in mind that the sick person understands rehabilitation as problematic, because their baggage of experiences, relationships and historical conditions can make this process of change even more challenging¹¹.

It is clear that becoming ill does not affect just one person, but changes everyone's life, which also influences the financial condition of this group. According to the PNH, the network of people affected by illness is characterized by the active and creative participation of a series of actors, who come together to face the problems that arise, in addition to articulating this new reality¹¹. In the majority of cases, close family members are unable to work because they have to spend most of their time caring for the cancer patient, resulting in a reduction in financial resources²⁷.

During the course of cancer treatment, many challenges arise and, in order to better discern the courses of action to be taken, it is necessary to have a solid support network that helps day after day in this process. The family was a central figure in the support network of the young women undergoing cancer treatment in this study, and often provided them with strength and refuge. The news of a cancer diagnosis and the experience of treatment, when

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

shared with people you trust, makes suffering easier to bear and the process as a whole less painful thanks to mutually-directed emotional care¹³.

Studies of women with breast cancer who have undergone the mastectomy procedure, for example, show that the emotional support of people with trusting relationships are important factors in facing the reality of experiencing a mutilation process and maintaining habits related to health maintenance²⁸. These relationships offer protective factors at a psychological and social level for cancer patients, where increased proximity, improved quality of relationships and the need to adapt and make support groups more flexible contribute to unity in times of difficulty²⁹.

The fact that the support of friends was portrayed substantially when these relationships were already extremely solid before the diagnosis, is in line with studies that report that friendships that remain and intensify during the course of these women's challenging new reality, help them cope with emotions, difficulties and overcoming them³⁰. On the other hand, when these bonds of friendship break down during the course of therapy, this process becomes even more painful for women with cancer³⁰.

Religiosity and spirituality in their different forms of expression were also identified as fundamental links in the support network of young women. Because of the intense influence of religiosity and spirituality, scientific evidence reinforces the importance of encouraging and understanding each patient's beliefs, since this contributes to understanding psychosocial adaptations to cancer diagnosis and treatment^{29,31}. Furthermore, the search for God or other religious/spiritual aspects is corroborated by the literature, in which they are often the first contact and main refuge in the face of the adversities imposed by treatment, and others correspond to a more intense strengthening of faith³⁰.

In this sense, it is necessary to identify and recognize the patient's support networks during treatment, as these can provide health professionals with the tools to direct their actions and care towards the family and the hospitalized patient more appropriately³². Thus, guaranteeing a voice to the patient and to those who are recognized as members of her support network, and providing sensitive listening, makes it possible to share fears, anxieties and expectations about her clinical condition, so that subjectivity involves this woman in her care plan and she sees the professional nurse as part of her social support network.

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

The work of the nursing team was pointed out as a fundamental element of the support network for young women undergoing cancer treatment, as the participants used these professionals as a reference when they needed to ask questions and explain their doubts. Nurses work at different levels in relation to cancer diagnosis. Although it is a long and debilitating process for the person affected, when information and guidance is provided horizontally and support is given beyond scientific knowledge, it brings these individuals closer together and, consequently, provides effective care that promotes a better quality of life³³.

Work based on the humanization of care and carried out holistically allows women to feel safe and more motivated to face the obstacles of cancer treatment, in which the emotional support provided by health care workers makes a difference in these women's daily lives. This allows the psychological changes and physical and social limitations to be mitigated by the support they receive³³.

The posture of the professional in enabling communication based on a multivector, networked dynamic, where the processes of health production and subjectivity can be expressed, allows young women to share their desires and experiences¹¹. The creation of this bond, in turn, can and should be initiated from the first contact and at different times during care, when it is possible to provide a quality welcome in order to recognize complaints as real and legitimate health needs. Thus, communication is highlighted within the PNH's welcoming guideline, as it makes it possible to recognize singularities and offer timely, targeted and effective care¹¹.

It is therefore clear that psychosocial support for young adults, especially, is essential in this context, where with the support of partners, children, family, faith and the multidisciplinary team, it is possible to provide less comorbidity together with a better quality of life³⁴.

FINAL CONSIDERATIONS

Young women undergoing cancer treatment characterized their support network, outlining their family as an important and indispensable link of care, attention and support. As a result, family ties became more effective and stronger after the impact of receiving the diagnosis.

The issue of seeking faith and religiosity was reported with emphasis in the study, mainly in order to optimize the support network and help overcome the diagnosis and treatment

SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

of the disease, minimizing the impact on the experiences and feelings of a person with cancer. Nursing professionals, in turn, were cited by the women as guiding the therapeutic process, through their constant empathy, humanized care and the provision of clear guidance, in order to take into account the patients' understanding and questions. In this context, we can see the importance of using the principles and guidelines of the NHP, especially in relation to the welcome that should be advocated during patient care. Nurses were also considered to be an important part of the participants' support network during the cancer treatment process.

As a limitation, this study was carried out during the Covid-19 pandemic, which made it difficult to reach these women. In addition, talking about the experience of cancer and the existence or not of a support network is also a challenge for young women, often causing discomfort and/or shame in exposing their reality.

For nursing, this study contributes to the awakening of care that is always humanized, empathetic and attentive to the integral observation of these patients, contributing significantly to the conduct and success of cancer treatment. It is also believed that the results obtained can contribute to the construction of knowledge in the field of nursing care and research, in order to instrumentalize this science on the support networks of young women undergoing cancer treatment.

This prompts the development of research aimed at understanding the feelings experienced and the reality of the people who make up the support network of young women undergoing cancer treatment, given that these perceptions can also help them cope with the challenges imposed by the disease and therapy, by considering those who inspire strength and courage.

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SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

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SUPPORT NETWORK FOR YOUNG WOMEN UNDERGOING CANCER TREATMENT

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