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MENTAL HEALTH OF PEOPLE UNDERGOING ONCOLOGICAL TREATMENT FOLLOWED-UP BY A SUPPORT ASSOCIATION: AN EXPERIENCE REPORT BY MEDICINE STUDENTS

SAÚDE MENTAL DE PESSOAS EM TRATAMENTO ONCOLÓGICO ACOMPANHADAS POR UMA ASSOCIAÇÃO DE APOIO: UM RELATO DE EXPERIÊNCIA DE ACADÊMICOS DE MEDICINA

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Abstract: The current study aims to introduce the experience of Medicine students during internship practices held at a Support Association for People with Cancer in a municipality of Rio Grande do Sul. This experience consists of practical and educational extension activities linked to the Curricular Component on Public Health I of the Medicine course at a university located on the Rio Grande do Sul. The institution has the internal characteristics of a house, for users undergoing oncological treatment and their caregivers. The activities were carried out from May to June, 2022. During participant observation, the importance of humanization and valuing the individualities of users, through the creation of bonds, the stimulation for socialization and the development of dynamic and creative activities, which promote the mental health. In order to carry out the extension activity, music therapy tools were used, with a view to providing users with moments of relaxation, conversation and, mainly, disconnection from the heavy and limiting atmosphere associated with the diagnosis and treatment of cancer. This work highlighted the importance of mental health care for people undergoing oncological

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treatment, with socialization activities being tools that contribute to the production of this care.

Keywords: Medicine, mental health, neoplasms, socialization.

Resumo: O estudo tem por objetivo apresentar a experiência de acadêmicas do curso de Medicina durante as práticas de estágio realizadas em uma instituição de Apoio a Pessoas com Câncer de um município do Rio Grande do Sul. A experiência consiste em atividades práticas e de extensão vinculadas ao Componente Curricular de Saúde Coletiva do curso de Medicina de uma universidade do Rio Grande do Sul. A instituição tem características de uma casa, com acomodações para usuários que realizam tratamento oncológico e seus acompanhantes. As atividades foram realizadas no período de maio a junho de 2022. Durante as práticas, identificou-se a importância da humanização e da valorização das individualidades dos usuários promovida por meio da criação de vínculos, do estímulo à socialização e do desenvolvimento de atividades dinâmicas e criativas que promovem a saúde mental. Para a realização da atividade de extensão, utilizaram-se ferramentas da musicoterapia, a fim de proporcionar aos usuários momentos de descontração, diálogo e desconexão com a atmosfera pesada e limitante agregada ao diagnóstico e ao tratamento do câncer. O presente trabalho evidenciou a importância do cuidado em saúde mental das pessoas em tratamento oncológico, sendo as atividades de socialização ferramentas que contribuem para a produção desse cuidado.

Palavras-chave: Medicina, neoplasias, saúde mental, socialização.

INTRODUCTION

Oncological diseases are defined as one of the major causes of death in the world, fatally affecting about 9.6 million individuals in the year 2018, characterizing themselves as one of the biggest and most complex public health problems to be faced, due to their epidemiological, social and economic magnitude (PAHO/WHO, 2020).

The diagnosis of cancer carries a range of negative and pessimistic feelings that, combined with the lack of a precise prognosis, bring uncertainties and anxieties to both the patient and their support network as well as the health professional.

This disease, in addition to affecting physical conditions, is responsible for radically transforming the habits and experiences of those affected. Furthermore, with the

diagnosis, new feelings, doubts and worries arise that, if neglected, can lead to damage to the mental health of the individual and their caregivers (TESTOM *et al*., 2018).

Thus, it is essential to consider the psychosocial context of cancer patients and their families, since the diagnosis, as well as the chemotherapeutic and/or radiotherapeutic treatment can bring numerous transformations in the routine and physical conditions, such as changes in body image, a greater dependence on third parties, limitations in the accomplishment of activities and tasks, dietary restrictions and social isolation.

These changes can culminate in psychological suffering, evidenced by the symptoms of depression, anxiety, manifestation of thoughts of hopelessness, feelings of fear, uncertainty about the future and dissatisfaction with body image (ONCOGUIA, 2022). Furthermore, in recent studies with people in cancer treatment, it was identified that about 31% suffer from anxiety and about 26% are affected by depression (FERREIRA *et al*., 2019).

From this perspective, as a strategy of approach in the care of cancer patients, the role of the social network during treatment is considered important, such as family, community, support institutions, and health services.

Social support can be defined as the provision of information and material assistance by groups and/or people, who establish systematic contacts with an individual, resulting in positive emotional and behavioral effects, thus being an exchange in which both parties are benefited.

The social environment is a protective factor in the prevention against diseases and in the maintenance of health and well-being when it offers support. Otherwise, it can also be stated that ineffective emotional support and insufficient social network are predictors of depressive symptoms during treatment (DA SILVA *et al*., 2020).

Within the scope of health services and support institutions, investments should be made in strategies to qualify teams for the humanized care of cancer patients with a focus on mental health, quality of life, well-being and improvement of approaches in palliative care, since this theme has been pointed out as inefficient in academic training (RIBEIRO, POLESL, 2019).

Medical professionals have several possibilities of action in this field, especially when the objective is to improve the quality of life of these patients (RIBEIRO, POLESL, 2019). One of the strategies for qualifying medical practice is the deepening of this theme in academic training in curricular activities of teaching, research and extension in order to equip them for comprehensive care that encompasses the technical and human condition, as well as respect for the dignity of the patient and their families during the different moments of treatment (CORREIA *et al*., 2018).

Thus, the present report aims to explore the experience of medical students during the internship practices carried out in an institution that welcomes people with cancer in a municipality on the western border of Rio Grande do Sul. This work is justified by the need to share information and academic experiences in the care of people with cancer, with a focus on comprehensive care, considering them as human beings full of feelings, experiences and sensations that go far beyond the biological change that occurs in their organisms.

MATERIALS AND METHODS

This present study is descriptive in nature, where the experience of activities developed by medical students will be reported, during the internship developed in an association that provides support for people with cancer, located in a municipality of Rio Grande do Sul.

The experience report is configured as an important scientific product in contemporaneity, as it presents a theoretical-practical construction that is proposed to the refinement of knowledge about the experience itself in a certain cultural and historical context, from the perspective of the subject-researcher. This type of product unfolds in the search for innovative knowledge (DALTRO; DE FARIA, 2019).

The practical activities are linked to the curricular component of Collective Health I, attended in the first semester of the Medicine course of a public university in Rio Grande do Sul. These are practical and university extension activities carried out in the care network devices of the municipality, with groups of approximately five students guided by a university professor and by preceptors of the services. The activities aim to provide articulation with the theoretical aspects studied in the curricular component such

as the integrality of care, the humanization of health, access to health services, equity and social participation.

The association where the experience was carried out has been providing support to people with cancer since 2013 and since then has served about 1,072 people. It is a non-profit entity, founded by a group of volunteers who had frequent contact with cancer patients and diagnosed the need for support environments, characterizing itself as a Civil Society Organization (CSO), which serves free of charge people diagnosed with cancer in a situation of social and personal vulnerability.

This association is also distributed in 13 other municipalities of the state of Rio Grande do Sul, where some of the main cancer treatment centers are located. The entity has already served more than 23,000 people. In 2022, it had approximately 4,589 users with active registration.

The association has a support house, which is also a reference for patients from 11 other municipalities. In this house, citizens, users and family members receive all structural and social assistance during treatment, having at their disposal dormitories, four meals a day, psychological and social work care, nutritional guidance, integrative activities, support groups and other tools aimed at alleviating the effects of cancer treatment. It is an entity that survives through donations. For this reason, it has many partners in the community and different activities for raising funds.

The institution has internal characteristics of a house, with 24 accommodations for users and their companions, in addition to a large kitchen and dining room, pantry, living room, room for Reiki, space for holding psychological support groups, therapeutic workshops and income generation, room for informative meetings for users and family members and a patio for the development of sustainable and therapeutic projects.

The curricular activities in this institution were carried out once a week from May 5 to June 5, 2022, representing a total workload of 20 hours, of which 10 hours were observational practice activities and 10 hours were extension activities.

During the observational practice, students were able to follow the routine of the service, and participate in the interactions between users, such as: group meals, the chimarrão circle in the courtyard, the moment of watching television, separating bottle

caps, playing cards, as well as lectures and workshops. The academics also developed an extension action with the aim of contributing to the institution from the needs and interests of the team and users.

The extension action focused on promoting mental health care and targeted the institution's users. It consisted of a dynamic activity based on the documentary "Alive Inside" (MCDOUGALD, SCULLY & ROSSATO-BENNETT, 2014). The strategies used were: individual dialogue with users, selection of songs of users' preference and conversation circle with the use of music therapy tools - a moment in which the thoughts, memories, and feelings of the users were explored when listening to the music. Approximately 12 users, 12 companions, a social worker, a psychologist and five medical students participated in the activity.

Participation in the extension action occurred voluntarily, and the group of students sought to adopt a posture of listening and welcoming with respect to life stories and expressed feelings. The extension action was accompanied by the institution's psychologist and the responsible social worker, especially as support for the group in case some songs aroused feelings of sadness, with the need for individual reception.

RESULTAS AND DISCUSSION

The activities carried out in the association added benefits to both the professional training and the personal experience of the students. Initially, when faced with the expectation of the first field practice of the medical course, the academics constructed several thoughts on the theme that involves the universe of people living with cancer.

However, during the practice, it was possible to perceive that most of these constructions consisted of misconceptions. While waiting for a sad environment with little participation of users, there was the perception that the reality of the institution was different since the group was received with welcome and willingness by users and their companions, who were willing to contribute to academic training, even those who were facing difficult moments of treatment.

In the first interaction with users and the support house, it was possible to participate in a Mother’s Day action organized by the association in partnership with

volunteer students regarding "caring for those who care". The action consisted of a lecture whose objective was to raise awareness about the importance of looking at the mental health of caregivers of cancer patients, valuing their feelings and anxieties.

In common sense, there is the idea that the sufferings and afflictions of caregivers do not have the same importance as those of the cancer patient. In this context, it should be noted that family members and caregivers are also going through changes in their daily lives, with new adaptations, doubts before treatment and that, many times, they feel overwhelmed with care, needing reception and actions of social and health services (LINS et al., 2021).

The lecture helped family members and companions understand that their feelings are important and should be expressed. In addition, the need to seek support from other networks such as family, social network and health professionals to share responsibilities, anxieties and patient care. For the group of medical students, the lecture aroused greater awareness of the importance of directing care actions to the caregiver, understanding that this approach is part of comprehensive care.

In the second contact, it was possible to break a barrier of fear and insecurity that users showed with the group on the first day. For this, the students sought to conduct individual conversations with users and their respective companions, in order to better understand their life stories, and their experiences in the institution, without focusing on the diagnosis of the disease.

In the first contacts, most users addressed the group in a wary and succinct manner. However, the strategy of letting the conversation occur spontaneously, without defined scripts, allowed them to express themselves and address what they felt comfortable about their lives.

This strategy provided moments of listening and exchange between the group and the users, which allowed learning for the students, as the group learned about countless life stories, of overcoming, of struggle and pain, but also funny stories of the daily lives of users. Thus, it was possible to learn more about their jobs, children, grandchildren, hometown, treatment, and, above all, the construction of bonds with these users.

During conversations with users, the group noticed a unanimity of praise regarding the welcome in the institution, mostly centered on the care, respect and humanized attention of professionals with users. These reports contrast, once again, with the group's expectations that it would find a less welcoming environment and more centered on the biomedical model.

On the contrary, it was perceived that the professionals responsible for the house treat users as human beings weakened by the disease, but without minimizing their tastes, feelings, anxieties and desires. In this way, the importance of building a bond between users and professionals in the search for an effective and humanized treatment is highlighted (ANACLETO, 2020).

It was also observed a valorization of the feelings and sensations experienced by users and family members, different from what is commonly observed in the literature about some services, where these aspects are neglected in the treatment and that contribute to the incidence of psychic disorders in cancer patients (FERREIRA et al., 2019).

Thus, the work carried out by the institution provided the students with reflection on how fundamental this attention focused on the humanization of care is. The primary function of support houses is to employ holistic and human care to those who are in it to provide physical and emotional well-being through a multidisciplinary team (FERREIRA et al., 2015).

To carry out the extension action, the students, in dialogue with the professionals and users of the association, organized a dynamic activity, in order to provide users with moments of relaxation, dialogue and, mainly, disconnection with the heavy and limiting atmosphere added to the diagnosis and treatment of cancer, in line with the way of working already carried out by the association.

The choice of the theme worked on in the extension action, occurred during the observation activities, in the process of understanding the role of the support house for users and companions. It was noticed that the treatment offered by the institution helps them in different spheres of life, from material support to support for social and psychological aspects.

The need for a special look at the mental health of these users was identified, since they face changes and challenges in their lives and routines in the face of a cancer diagnosis and therapeutic processes such as chemotherapy and radiotherapy. In this way, the group in dialogue with the professionals listed for the extension action an activity focused on the promotion of mental health care.

To carry out the action, the group was based on a documentary addressed in the curricular component of Introduction to Anthropology and Sociology, of the Medicine course, which is called "Alive Inside" (MCDOUGALD, SCULLY & ROSSATO-BENNETT, 2014).

In this production, social worker Dan Cohen, through his contact with long-stay institutions for people with mental illnesses, such as Alzheimer's and dementia, introduces a new dynamic of treatment with the elderly, in which Cohen seeks to know the life history of these individuals and identify the songs that recall striking moments for them, in order to awaken sensations and feelings little valued in the treatment.

The results of Cohen's experience are surprising, so that elderly people who were practically motionless begin to initiate dance movements; people who no longer spoke begin to show attempts to sing songs, thus explaining the therapeutic importance of music in awakening sensations and feelings. In view of these benefits, the group chose to take advantage of music as a therapeutic strategy to provide users with a moment of relaxation and reconnection with their stories, memories and feelings.

To carry out the extension action, the students proposed that users choose the songs. Thus, the group used individual and informal conversations with users and their companions, in order to learn about their life stories, hobbies, interests, work and, especially, develop an approximation with them. During the conversation, they discussed the favorite songs, asking them about a song that would arouse feelings or some positive or negative memory.

On the day of the extension action, a circle of chairs was organized in the courtyard and a sound box was used to play the songs previously chosen by the users. White papers and pens were also offered to those who had not chosen their music in previous conversations. Thus, armed with the songs chosen by each person and with the

group comfortably seated in their places, the dynamic was started with a brief presentation of the group and guidelines on how it would work.

The dynamic would proceed in basically three stages: 1) a stretch of a random song among those chosen by the participants would be played; 2) people should try to guess which participant of the dynamic had chosen the song; 3) the user responsible for choosing the music would introduce himself and, if he felt comfortable, could explain to the group the reason why he chose a certain music and what feelings it aroused in him.

In the first songs to be played, it was possible to notice the group still reclusive and wary about the dynamics. However, the idea of proposing a guess of who had chosen the song helped to relax and promote a more effective socialization.

Throughout the dynamic, there were diverse testimonies, of longing, of happiness, of joy, of sadness, of love and several other feelings. Many chose "gauchescas" songs, since a large part of the public was from the interior of Rio Grande do Sul and older, such as Monarcas and Mano Lima, and also eclectic songs, with artists such as Coldplay, Roberto Carlos, and Anavitória.

The reasons for the choice were also diverse, some recalled songs of youth, songs of happy moments, and many of them had specific reasons, such as, for example: a lady who brought up strong emotions when choosing a song that her son, recently deceased, sang every day for her.

In addition to promoting an opportunity to remember, reflect and feel, the proposed action promotes something considered essential by numerous experts in the areas of health and psychology, which refers to the socialization and inclusion of participants.

The group of students sought, through this activity, to bring to the users a moment of relaxation, even if for a few moments, in an attempt to "reduce" the baggage attached to cancer treatment and provide a moment of happiness with the awakening of different affective sensations.

Some situations aroused collective insecurities in the group, which felt unprepared to deal with the awakening of emotions and memories that could trigger sadness. However, equipped with the support of the institution's psychologist and prior preparation

to deal with these situations, the dynamic took place without generating tensions, causing a feeling of satisfaction, support and learning for the academics.

Finally, the activity contributed to understanding how important a humanized care focused on mental health, socialization and the singularity of the cancer patient is. It was observed that it was possible to promote moments different from those related to the rigid and restricted routines, the limitations and negative feelings arising from the cancer diagnosis.

During the practices, it was also possible to perceive that the institution's approach is based on the perspective that we are all social beings. So socialization is one of the key points of the care provided. The interaction between the users of the institution is fundamental in this process of physical and mental care offered during the treatment. Many of them, when arriving at the house, feel apprehensive and afraid of the treatment and what may happen in the future. However, communication and identification among users help not only to reduce this fear, but also to create bonds through the exchange of experiences, which helps them in the treatment (DOS SANTOS et al., 2018).

In addition, the users of the institution are often far from their homes and their municipalities. Therefore, the coexistence offered by the organization is also important for them to talk and exchange experiences about the insecurities and difficulties they encounter because they are in a different municipality from theirs, with other services and professionals, in such a way that they can alleviate the suffering in relation to these concerns.

The identification that occurs between users is also fundamental in the care, because the employees, even though they help with the various activities carried out in the institution, cannot bring horizontality when relating to the users. The interaction between the users provides the sharing of experiences and feelings, which makes the institutions with these characteristics more welcoming regarding mental health care (DOS SANTOS et al., 2018).

In society, mental health care for people in cancer treatment is a challenge. Among the challenging situations is the social pressure that everyone should be well at all times, regardless of the situations they are facing. There is also the change in relational treatment that occurs when people find out that someone has cancer. These highlighted points affect

patients, because, in addition to judging them as fragile, they require them to be in a constant state of happiness and gratitude, which is not something natural to human beings.

In this sense, spaces for coexistence and exchange of experiences such as the institution visited during academic practices are important, as they value the mental health of these individuals and help them to go through this difficult time in a more supported and shared way.

However, currently, the number of institutions that do this careful work with users in the public system is scarce in Brazil. There is a need to strengthen the humanization of care, a better articulation between the public, private and informal systems of care, the economic and technical-assistance conditions (SOARES, SANTOS, ARRUDA, 2017). Therefore, these aspects need to be considered in the organization of services and public policies aimed at people with cancer.

Furthermore, in care, it is fundamental to understand that all patients, despite receiving the same diagnosis, deal with this information in different ways. It was possible to observe during the practice that each one has their individuality and the discovery of cancer has a distinct burden, depending on the subjectivity and mental health of each patient, the context in which they live, the support network and the care received by professionals. Even in cases of recurrence of cancer, the person may react differently from how they reacted in their first diagnosis.

In this context, the professional who will care for these people, whether in the hospital or in territorial care institutions, needs to consider the individualities, as well as welcome the feelings of users, whether positive or negative, understanding this welcome as fundamental in the treatment.

When this welcome does not occur, and the bond is fragile, a barrier is built in the care, preventing, in some cases, the completion of cancer treatment in the correct and accompanied manner (FREITAS et al., 2022).

Regarding the institutions that welcome this public, these can contribute to the user and companion understand the treatment from a new perspective. For this, they must offer welcome and different socialization activities in order to promote the resignification of treatment and new experiences, understanding that the diagnosis of cancer does not

prevent them from doing things that bring them pleasure and happiness, as was experienced by the group in the observed institution.

In the component of Collective Health I, it was studied that health is not only the absence of disease, since the person may not have a disease installed, but not feel healthy. This perception occurs for different reasons, among them the exposure to social, economic vulnerabilities such as the difficulties access to health services and treatment, access to housing, transportation, work and among other needs.

However, it is possible to reflect that, in the case of people in cancer treatment, it was perceived that health is also made in the presence of the disease, when the person even in the face of vulnerabilities caused by the symptoms of the disease, or even by the symptoms of chemotherapeutic and radiotherapeutic treatment finds moments promoting health, whether by the welcome, material and psychological support to their needs, spaces to share their anxieties, longings, talk about themselves and also be a source of help to other people.

It is important to emphasize that, in the care of a person with cancer, a multidisciplinary team is also necessary, which uses specific tools in the identification of the needs of its public.

Among the approach tools there is a Canadian tool for controlling and analyzing the mental health of patients in chemotherapeutic and radiotherapeutic treatment called "Distress Thermometer". This tool is new in the national context, but is already carried out in countries abroad, using brief questions filled out by the patient themselves when attending a treatment session or a consultation.

Through these answers, it is possible to predict a scale of "distress", stress, anxiety and depression, providing the individual, in scales of risk of psychic disorders, a more effective access to the appropriate professionals. In addition, the frequency of applications allows to monitor the psychological development of patients and identify early signs of risk to mental health (MARQUES et al., 2022).

In oncology, one of the branches that needs more attention is psycho-oncology, requiring more research, work and discussions about the subject. However, it is observed in the scientific, academic and hospital environments the creation of groups and

institutions supporting cancer patients that stimulate this human and social care, as well as the realization of specific congresses, such as the International Congress of Psycho-Oncology, which in 2023 held its second edition.

In addition, it is also considered important the approach of this theme in curricula of the health area, in curricular activities of teaching, research or extension, and not only in extracurricular activities. This focus in graduation, based on referentials of humanized, integral and interdisciplinary care, may qualify the performance of students and future professionals, demystifying stigmas related to the theme and expanding the scope of therapeutic actions.

CONCLUSION

This study highlighted the importance of support houses for people undergoing cancer treatment, with a focus on the biopsychosocial care of users and their companions. In addition, this experience report also reinforces the importance of addressing the mental health of people undergoing cancer treatment, with socialization activities being tools that contribute to the production of this care.

During participant observation, the importance of humanization and the valorization of the individualities of users, promoted by professionals, through the creation of bonds, the encouragement of socialization and the development of dynamic and creative activities that promote the health of mind and body, given the limitations of the oncological diagnosis, was identified.

The positive characteristics observed in the institution are due, in large part, to the work of the local team in valuing and supporting the user from the moment of entry into the house until the end of treatment. In this way, the discussion about the need for valorization and encouragement of support institutions for people with cancer is of utmost importance, since these assume a fundamental role in the effectiveness and continuity of cancer treatment.

Throughout this study, the lack of research that shows the importance of these institutions in the transversal care of the patient and their family was observed, contributing to the invisibility of the role that these organizations play. Thus, the group

seeks, through this report, to contribute to social awareness about the importance of institutions and qualified professionals in the multidisciplinary treatment of people with oncological diseases.

For medical academics, the experience contributed to complement the theoretical classes of the Collective Health I component, being possible to observe in practice elements of integrality, humanization of care, and conceptions related to the health and disease process.

This articulation between theory and practice allowed the construction of important skills for academic training such as listening, dialogue, group work, reflection, and the organization and execution of an extension action. In addition, it contributed to the understanding of the organization of the local care network accessed by users in cancer treatment, the potentialities and challenges, constituting important information to share with other teams and users in future practices.

Finally, it is important to note that this work is limited to a single support institution and a restricted group of users and companions, so that the results obtained by this report may be different in other contexts and other institutions.

The present writing seeks, therefore, to encourage research that analyzes a greater range of support institutions for people with cancer at the regional and national levels. This expansion seeks to foster the work of these organizations and also strategies of socialization and the applicability of playful and recreational activities, such as the use of music, in the prevention of psychic disorders and in the maintenance of well-being.

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