



Signifying the Voluntary Work at an Oncologic Support House

Significando o trabalho voluntário em casa de apoio oncológica

Significando el trabajo voluntario en casas de apoyo a pacientes oncológicos

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ABSTRACT

Objective: Understand the meaning attributed by people who have developed voluntary work in cancer support services. **Method:** This is a qualitative study, whose theoretical framework was Symbolic Interactionism, carried out with ten volunteers in an oncology support house in a medium-sized municipality located in southern Brazil. Data collection took place between June and August 2016 through open interviews, organized with the help of the IRAMUTEQ software and thematic content analysis was carried out. **Results:** As a result, three categories emerged that discuss motivation and the desire to dedicate themselves to others, obstacles to volunteer work and personal growth and satisfaction in giving to others. **Conclusion and implications for the practice:** voluntary work involves cultural issues, beliefs, charity and love for others, but it can generate feelings of suffering and helplessness in addition to financial difficulties for its execution. Despite the difficulties encountered, it provides personal and professional recognition to those who perform it.

Keywords: Volunteering; Oncology; Cancer Institutes.

RESUMO

Objetivo: Compreender o significado atribuído pelas pessoas que desenvolveram trabalho voluntário em serviço de apoio oncológico. **Método:** Trata-se de estudo qualitativo, que teve como referencial teórico o Interacionismo Simbólico, realizado com dez voluntárias em uma casa de apoio oncológica em um Município de médio porte localizado no sul do Brasil. A coleta de dados ocorreu entre junho e agosto de 2016 por meio de entrevistas abertas, organizadas com auxílio do software IRAMUTEQ e realizado análise de conteúdo temática. **Resultados:** Como resultados, emergiram três categorias que discorrem sobre a motivação e o desejo de dedicar-se ao outro, os entraves no trabalho voluntário e o crescimento e satisfação pessoal na doação ao outro. **Conclusão e implicações para a prática:** O trabalho voluntário envolve questões culturais, crenças, caridade e amor ao próximo, mas pode gerar sentimentos de sofrimento e impotência além de dificuldades financeiras para sua execução. Apesar das dificuldades encontradas, propicia reconhecimento pessoal e profissional a quem o realiza.

Palavras-chave: Voluntariado; Oncologia; Institutos de Câncer.

RESUMEN

Objetivo: Comprender el significado atribuido por las personas que han desarrollado trabajo voluntario en los servicios de apoyo para el cáncer. **Método:** Este es un estudio cualitativo, cuyo marco teórico fue el Interaccionismo Simbólico, realizado con diez voluntarios en casas de apoyo a pacientes oncológicos en un municipio de tamaño mediano ubicado en el sur de Brasil. La recopilación de datos tuvo lugar entre junio y agosto de 2016 a través de entrevistas abiertas, organizadas con la ayuda del software IRAMUTEQ y el análisis de contenido temático. **Resultados:** Como resultado, surgieron tres categorías que reflexionan sobre la motivación y el deseo de dedicarse a los demás, los obstáculos en el despliegue del trabajo voluntario, el crecimiento personal y la satisfacción de dar a los demás. **Conclusión e implicaciones para la práctica:** El trabajo voluntario involucra cuestiones culturales, creencias, caridad y amor por los demás, pero puede generar sentimientos de sufrimiento e impotencia además de dificultades financieras para su ejecución. A pesar de las dificultades encontradas, proporciona reconocimiento personal y profesional a quienes lo realizan.

Palabras clave: Voluntariado; Oncología, Institutos de Câncer.

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INTRODUCTION

Despite technological advances in health, cancer remains a worldwide public health problem,¹ constituting the second leading cause of general mortality in Brazil in recent years.² The increase in the number of neoplasia cases and the technological complexity that involves its treatment had an impact on the development of regionalized therapeutic centers for oncology, usually located in large cities, which have the necessary resources to assist such patients.

In addition, the emergency in receiving cancer patients and their families during antineoplastic treatment, caused Support Houses to appear, in an attempt to shelter, welcome and meet the needs of these people, who are experiencing a difficult and challenging phase.³ The Support Homes offer non-profit assistance, with volunteer staff members who offer assistance to the institution and people in conditions of illness.⁴

Voluntary work has the function of offering help to needy individuals or communities, in an altruistic and, necessarily, spontaneous way.^{5,6} In addition, as a third sector, voluntary work is composed of people who perform social work and who can reach areas of the various services that the Public Sector is unable to effectively cover.

Around the world, volunteering has evolved from a social outlet that comes from non-governmental organizations and service agencies, becoming a popular phenomenon, which has increased social awareness for its achievement.⁶ Even with the cultural expansion of solidarity in society over time, volunteer work is still an identity under construction in our country. This type of work, according to scholars, is permeated by motivations, desires and values that are being unveiled over time.⁷

The motivation to carry out voluntary work encompasses several dimensions and multiple influences, being considered complex, social, personal and subjective.⁷ This type of activity allows people to develop skills, learning, knowledge, preparation for a future professional career, developing bonds and greater self-knowledge.

In oncology, voluntary work assists in the development of skills for new and future professionals, in order to create professional experience with cancer patients, influencing human and compassionate care.⁸ Furthermore, the work in Oncologic Support Houses requires physical and emotional preparation on the part of those involved, in addition to extreme dedication, given the need to offer support and care at a particularly special time in the lives of patients and their families.³

In this context, one asks oneself on the meanings that lead the person to start voluntary work in an Oncologic Support House, taking into account the motivations that keep them in this role and the preparation time required for this voluntary activity? To this end, the objective of this research was to understand the meaning attributed by people when starting voluntary work at an Oncologic Support House.

METHOD

It is a qualitative, descriptive and exploratory study, which had as a theoretical reference Symbolic Interactionism (SI), considered one of the most appropriate approaches to analyze processes of socialization and re-socialization, as it is a sociological approach brought from the individual meanings, as opposed to functionalism and pre-established social rules. In this way, the IS will go beyond social actions and condition society's rules.⁹ The basis of the meaning is found in the social conduct, in which significant symbols emerge. Only when the individual identifies with such symbols the meaning does become conscious. Mental processes are related to this meaning of things, and mentality resides in the organism's ability to indicate that element of the environment that responds to its reactions, in order to be able to control such reactions in various ways. And, control is made possible by language, which emerges the mind field of what is lived and experienced.¹⁰

The development of the study took place with the people who performed volunteer work in an Oncologic Support House, an institution located in a medium-sized municipality in southern Brazil. It attends cancer patients, in any age group, proven to be without financial conditions, living in small municipalities, who need to move from their cities of origin to undergo treatment.

The place offers nursing services, physiotherapy, psychology, pharmacy, social assistance and legal advice, according to the demands of each user. It also counts on the support of volunteers who carry out home visiting activities, delivery of basic food baskets, manual activities, fundraising campaigns, among other activities with greater affinity.

The participants in this study were 10 volunteer people who worked at this institution during the period of data collection that occurred from June to August 2016. The total sample followed the principles of theoretical saturation. The inclusion criteria of the subjects were: Being 18 years old or being older, providing voluntary work in that Support House in activities that required direct contact with the patients. Criminal volunteers who provided services at the institution were excluded, on the understanding that these people were fulfilling a criminal obligation and not volunteering understood as an act of choice; what could present symbologies that would not meet the object of the research.

The open and individual interview was used for data collection, with the following guiding question: "How do you signify the voluntary work carried out in this Oncologic Support House? Other questions were also asked in order to deepen the theme, which were comprised of: "What are the difficulties faced for the development of this work?", And "For you, what are the benefits in carrying out this activity?".

The interviews were conducted individually in a private room at the Oncologic Support House, which preserved the participants' privacy. All interviews were recorded on audio and had an average duration of 45 minutes. Afterwards, they were transcribed in full and analyzed. For data analysis, the software IRAMUTEC (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*) was

used, which is an important tool to support the processing of qualitative data,¹¹ allowing for different processing and analysis of produced texts, such as: Classic textual statistics, research on group specificities, descending hierarchical classification, similarity analysis and word cloud.¹²

In this study, the word cloud was used for data processing. However, using the *software* does not complete the analysis, it merely instrumentalizes and assists this step, the interpretation of the data being an essential step and the responsibility of the researchers.¹³

For the construction of the categories, there was a convergence between the most frequent words identified by the *software* and content analysis, thematic modality, in three steps: 1- pre-analysis, moment of the floating reading of the interviews, with exploration of the material, and exhaustive reading of the data, highlighting and grouping the emerging points; 2- coding the messages to apprehend the nuclei of meaning, which were compiled, generating the thematic categories; 3- inference from the obtained data and the adopted theoretical framework. In this phase, the context of the language was analyzed, as well as the condition of the sender and its meanings.¹⁴

From the association of the results found in the analysis of the word cloud (Figure 1) and content, three thematic categories emerged: "Signifying the desire to dedicate yourself to the other one"; "Feeling helpless in the face of cancer: Difficulties in the voluntary work "; "Growth and satisfaction: benefiting from the donation to the other".

It should be noted that for the development of the research, all ethical and legal precepts regulated by Resolution 46/2012 of the National Health Council - Ministry of Health were respected. Approval was obtained from the Research Ethics Committee involving Human Beings at the State University of Maringá, according to opinion n° 1.666.380 and CAAE 57741316.0.0000.0104. All the guests accepted and signed the Free and Informed Consent Form (FICF). To guarantee confidentiality and anonymity, participants were identified by the letter V of volunteer, followed by a number that corresponded to the sequence of inclusion in the study, such as (V1, V2, ... and V10).

RESULTS

Ten volunteers from an Oncologic Support House participated in the study, all female, being between 25 and 90 years old. Two had completed high school and eight had completed higher education, of which three were postgraduates. With regard to the interviewees' occupational situation, two were unemployed, two retired and six engaged in paid work. Five of the participants declared that they had already done volunteer work in another location and with another population, as shown in Chart 1.

Regarding voluntary work, there are several activities performed by the interviewees, such as: Home visits, delivery of basic food baskets, handicrafts, fundraising campaigns; and, for volunteers who were psychologists, they offered psychological care to patients and family members.

The volunteers shared the meanings existing in the developed service, as well as the reasons that encourage its continuity, in addition to the problems faced in the daily life of this type of work. According to the word cloud (Figure 1), the most frequent words were directly related to the meanings that the participants attributed to voluntary work, supporting the categories identified in the data analysis, which allowed to know the experience of the participants in carrying out the voluntary work in oncology, the difficulties experienced, the benefits and learning provided in this context.

Signifying the desire to dedicate yourself to the other one

By signifying the desire to develop volunteer work at Oncologic Support House, the study participants pointed out the reasons that led them to carry out this activity, which had influences from various aspects, with emphasis on family and religiosity.

[...] came since being a child, a stimulus/incentive from my parents. Well, my parents work a lot with the voluntary issue within the Catholic Church. Since I was a child, I already knew that I had to do voluntary work, that has been taught to me since I was a child. [...] (V5).

The experience of having already experienced cancer, also proved to be a way to awaken the desire to help other people, in the sense that recognizing the situation that the other is going through brings greater meaning to the action developed with voluntary work in the chosen area.



Figure 1 – Word cloud provided by the *software* IRAMUTEC

Chart 1- Characterizing the volunteers from the Oncologic Support House of Maringá, Paraná.

Gender	Age	Degree of education	Profession	Previous voluntary work	Activities carried out as a volunteer at the Oncologic Support House
Female (V1)	38	Master in Public Health	Culinarist	Yes (Institutions and Associations)	Home visits; aid to the invoice sector and the culinary sector
Female (V2)	64	Master in Psychology	Psychologist	Yes (Church, needy families)	Home visits; assistance to the Board; care as a Psychologist in support groups for women with cancer
Female (V3)	46	Graduated. Psychology	Unemployed	No	Home visit; Distribution of basic food baskets; handicraft; aid for fundraising;
Female (V4)	37	Master in Organizational Psychology	Unemployed	No	Home visit
Female (V5)	25	Graduated. Psychology	Psychologist	No	Individual clinical psychological care (patient, family, adult and children)
Female (V6)	90	High school	Retired	Yes (helping patients in the community)	Home visit and administration assistance
Female (V7)	61	Graduated.	Retired and self-employed	No	Home visit
Female (V8)	27	Graduated. Psychology	Psychologist	No	Psychological care, counseling and therapeutic listening
Female (V9)	31	High school	Secretary	Yes (distribution of gifts to underprivileged children and soups for homeless people)	Recreational activity (bingo) for hosted patients; aid to the invoices sector; aid for fundraising;
Female (V10)	25	Graduated.	Office finance	Yes (in an institution for the elderly)	Recreational activity (bingo) for hosted patients; aid for fundraising;

Source: Data from the researchers, 2016.

In my case I already had cancer, six years ago I had breast cancer, it was a difficult time for me. So, today, being cured and being able to give support to those who are going through this moment is very rewarding. [...] (V3).

In addition to personal motivations, the offer of recruitment on social networks by the Oncologic Support House led the volunteers to reflect on the performance of the work and led them to search for information to do it. The encouragement of colleagues also proved to be important for the motivation of the volunteers, who showed interest in the work after the recommendation of other people.

I heard a lot about this Support House and I saw an advertisement on the social network that they were recruiting new volunteers, so I came, I found it interesting. [...] (V1).

[...] I heard about the voluntary work, but I have never had contact, then a friend of mine who is a nurse said: "Look, there is recruitment, do you want to take part and see how it goes?". Then I came! (V3).

There were several personal motivations that influenced the development of volunteer work, in summary: The family, the religiosity, the experience of having lived a cancer, the promotion on social networks and the encouragement of friends.

Feeling helpless in the face of cancer: Weaknesses in the voluntary work

Voluntary work in the oncology field can bring some difficulties, such as the manifestation of feelings of suffering and impotence in the face of terminal situations, imminent in many cases of cancer.

The difficulty is that, sometimes, you feel helpless, because we don't have the power to cure. (V4).

[...] the patients' losses. I carry out home visits to terminally ill patients [...]. We feel, each death is painful [...] (V1).

Another obstacle reported by the participants was reported by the volunteer psychologists, who experience the lack of appreciation of their work with the patients, who often do not continue the care. For them, patients' abandonment and absences

can be due both to the free character of the treatment and the lack of importance given to psychotherapy.

[...] there is a difficulty in the question of the commitment that people have with the treatment. I believe that because it is a free service, there is more lack and abandonment of treatment. You schedule and the person doesn't come. (V5).

One difficulty I encounter is that of not having a continuity of treatment, they start, but do not return. I go as a psychologist to do psychotherapy with cancer patients, but in fact, this is not how it works. They don't come back. (V8).

The lack of financial resources available to purchase inputs or medications for patients is also an obstacle to work, making it difficult to offer care and also causing an emotional impact for some volunteers.

When I realize that home is going through financial difficulties, sometimes to buy medicine, diapers and food to be able to meet the needs of patients, it hurts! It hurts to see that we do not have what is necessary to provide adequate support to patients. (V1).

On the other hand, the volunteers also face personal difficulties to carry out the work, such as the distance from the institution to the patients' homes, as well as travel expenses, considering that it is a job that does not involve payment or assistance with transportation.

[...] but the cost of coming and going is very high [...]. (V2).

The difficulties I see are the distance I live from the institution, because if I lived closer I could make more visits and could pass on the report of visits personally and more often. (V7).

The home visit has been an activity carried out by the Oncologic Support House for a long time, however, the acceptance of this activity by people with cancer does not always occur, as the testimony reveals:

Another difficulty is that people do not want to receive us in their homes, as they receive benefits from the institution and I think they think that with the visit we will see that they have conditions and thus their benefit will be cut. (V7).

The difficulties enumerated by the participants describe the daily work of volunteer work from the perspective of difficulties and obstacles that involve this activity. Such issues, despite making it difficult to exercise volunteering, do not prevent them from continuing in their activities that involve caring for others,

but demonstrate how the staff deal with the weaknesses found, encouraging them to continue the voluntary work process.

Growth and satisfaction: Benefiting from the donation to the other one and dealing with the weaknesses

Despite the difficulties existing in carrying out voluntary work, its performance adds individual benefits to those who do it, being signified by feelings of gratitude, satisfaction and recognition, as demonstrated by the participants.

For me, the benefit I get from this work is personal gratification. (V4).

[...] personal gratification, because when I go there I don't get anything in return, in financial terms. But just being there and seeing that you are helping someone is a huge benefit. (V8).

The benefit for me is personal! It is very good and rewarding to be a volunteer [...]. I feel good about doing this job [...]. (V10).

Voluntary work can reflect on the individual growth of the people who carry it out, since they manifest in their testimonies satisfaction, learning, growth and personal and professional recognition when exercising their function.

[...] it is good for the next one, this is very good! We grow a lot as a person, you value other things. I see that I have changed, today I have a slightly different look than I had before on things, I don't know, we grow a lot. (V2).

This work keeps me active professionally, keeps me known. It makes me realize recognition for work, it allows me to put into practice what I have learned. And it still allows me to meet fascinating people [...]. (V5).

The benefits arising from the performance of voluntary work evolve affective and positive aspects in people's lives, it was observed that this type of work is able to awaken humanization to those who do it, allowing for professional learning and personal reframing.

DISCUSSION

The accomplishment of the volunteer work in an Oncologic Support House was revealed as a process of reflection, motivations, challenges and gratitude, which permeate the daily struggle for a dignified and humane care for people with cancer outside their home and far from living with their relatives. The surroundings of the experiences of volunteer work translate as an opportunity to exercise care professionally, as well as the development of solidary and philanthropic skills.

According to the results of the study, there are several reasons that motivated people to do voluntary work. Family motivation is based on encouraging solidarity activities originating from parents or family members, aiming at maintaining tradition and building humanitarian beliefs and values that are taken into adult life. This family process can be observed as a transmission of knowledge among the family group, with a historical and cultural process involved, which is part of a social construction in the environment in which they live.⁷

On the other hand, religiosity, when able to stimulate the practice of voluntary work, brings with it feelings of altruism, which translates into an attitude of love for others, which involves help, renunciation and commitment on behalf of the other one. It is emphasized the intrinsic character of the motivation of the volunteer worker when exercising this function, in which these people dedicate themselves to care thinking about the well-being of the patients who will receive their attention, which is the main impulse for their work.¹⁵

Another aspect directly related to the motivations for carrying out voluntary work is recognized by the very identity of the role of the person who performs it. A common justification for carrying out voluntary work stems from the individual's individual experience, which is perceived in a more advantageous situation than those who will receive their assistance.¹⁶ Thus, the experiences previously experienced by the volunteers are a factor that stimulates the development of this action, motivating them to seek ways to carry it out.

In this study, in addition to the reasons already mentioned, recruitment through the social network and encouragement from colleagues was also mentioned. We emphasize the importance of communication as an important tool for promotion and dissemination, with high power to influence people in any area. This type of influence is used by human beings as a stimulus to get people to participate in causes they believe in.¹⁷ As a technological tool, social networks contribute to the dissemination and dissemination of important content, being part of the daily life of the population.

With regard to the daily work of volunteers, difficulties were also pointed out by the participants of this study, which range from specific issues in the oncology area, such as the feeling of suffering, helplessness and grief when living with a terminal situation, to the lack of financial resources of the institution and the person himself, and the physical limitation related to the distance between the volunteer's home and the Support House.

Working with people with cancer can trigger suffering for the volunteer worker, who starts to deal with feelings before few experienced, causing people to awaken defense mechanisms, such as denial. A study with volunteers who worked with children with cancer identified that, the evolution of the child's disease to death generated anguish for workers, who felt the loss of the patient significantly.¹⁸

Regarding the economic problems recognized by the research participants, such as the lack of financial resources and governmental support to fund the institution's activities, it is emphasized that, in another study carried out with volunteers, it was observed that, many times, the volunteers put themselves in the place of the public power, in order to provide adequate conditions for the people who receive their care.¹⁶ Because of this, frustration and the feeling of powerlessness can often be part of the daily life of the volunteers, who find themselves unable to effectively provide assistance to his patients.

Another obstacle in the accomplishment of the volunteer work, recognized by the psychologist participants was the lack of adherence to the psychological assistance offered to the people of the institution. This is because, they mentioned that people have difficulties in accepting it and maintaining the continuity of treatment after starting it. In the opinion of the volunteers, this behavior may be related due to the ease in offering treatment, such as the gratuity established by volunteering.

The results also demonstrate that voluntary work provides benefits to those who do it, meaning it as a rewarding, satisfying experience, and that promotes personal and professional growth. The satisfaction of volunteering for their personal contribution in the work process constitutes a unique motivation for the continuity of the profession or, even, the objective mission in this environment.¹⁵

Regardless of perceptions or opinions about volunteering, the performance of this job should be beneficial both for the person who performs it and for society, which is the main objective of this type of care.^{6,19} Studies indicate that this type of activity promotes a reciprocal benefit in human life, that is, it is beneficial for those who receive it and for those who perform it.^{20,21} In addition, the work of giving is anchored in the awareness of being of service to society, to others, fulfilling the role of citizen and experiencing the transformative potential that such attitudes represent for the individual's inner growth.²²

In this sense, on an individual basis, voluntary work may come to provide professional experience, individual growth and changes in the outlook on the life. This type of learning is directed to growth, in the sense of change in the human being so that he improves as a person. Thus, the final result of volunteering is more complex than just the final result of the work⁶: It affects in an individual and unique way each person who is dedicated to the other in a humanitarian and free of charge mode. In addition, it is a source of support and comfort for people who experience cancer treatment.^{23,24}

CONCLUSION AND IMPLICATIONS FOR THE PRACTICE

Voluntary work in an Oncologic Support House is surrounded by multiple meanings and diverse motivations, which involve beliefs, charity, love of your neighbor and even a cultural issue, and their understanding is complex and individualized. It was also

found that this type of work can bring some problems, such as the presence of feelings of suffering and impotence related to the specificities of cancer; the financial difficulties of the institution and the volunteers; and the physical delimitation when it prevents people from executing it.

However, the study also identified that this type of activity provides multiple benefits to those who perform it, including satisfaction, gratification and even personal and professional recognition, which are considered positive feelings for human beings.

In view of the humanization advocated by the Ministry of Health, deepening studies on this theme as the motivation for solidarity and citizenship actions is paramount. Thus, continuing with new studies on this topic can stimulate humanization practices in different health scenarios.

As a limitation of the study, it is pointed out that it was carried out only in one institution and with a limited population. However, the growing area of voluntary work reflects the need to develop more studies in this context.

AUTHOR'S CONTRIBUTIONS

Study design. Data acquisition and analysis, and interpretation of the results. Critical review. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Patrícia Bossolani Charlo. Study design. Conception of this study. Data analysis and interpretation of the results. Critical review. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Marcele Paiano, Maria Aparecida Salci e Catarina Catarina Aparecida Sales. Data collection. Critical review. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Julia Wakiuchi, Jéssica Manari Casado.

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