



SOCIAL WORKER INTERVENTION STRATEGIES IN PALLIATIVE CARE IN THE BRAZILIAN CONTEXT

¹Andrea Frossard* and ²Aline Baptista de Aguiar

*¹Professor at Brazilian National Cancer Institute - Palliative Care Unit.

Post-doctorate in Human Sciences. PhD in Social Work

²Student of Social Work at Estácio de Sá University. Scientific Initiation Scholarship

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ABSTRACT

Palliative Oncologic Care aims to offer comfort measures to patients who, without the possibility of cure, experience multiple phenomena the social issue. The research goal is to analyze on strategies of assistance in Palliative Care, from the concept of social pain with emphasis on the financial life of cancer patients and their support network.

The research was based with basis in the documentary investigation and of the bibliographic study (was use the integrative review method). The inclusion criteria defined for the selection of articles were: articles published in Portuguese and full texts that expressed the study on the theme with emphasis in in the perspective the Social Work. Articles that did not address the field of Palliative Care focusing on the social issue were excluded. The social worker should act towards make feasible social rights and refer patients to the necessary equipment and services, according to what was identified through the social study, and share information appropriately with the team as well. When a cancer patient is in Palliative Care, the financial costs for them and their support network have no definite end date due to the extent of the treatment that is only completed when life ends. It is found that the greater the access to public policies, the smaller the financial impacts will be and, consequently, there will be less suffering from the social dimension of pain.

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INTRODUCTION

According to data presented by the National Cancer Institute (INCA, 2017), it is estimated that the number of new cancer cases in Brazil for the 2018/2019 biennium is close to 600,000 each year. Among the numerous external causes, without taking biological and behavioral risk factors into consideration, one can point towards the increase in life expectancy of the population, the lack of policies for prevention and the precarization of the public health system.

Currently, cancer is emerging as a public health problem. The publication of Ordinance No. 2.439 / GM, of 08/12/2005, of the Ministry of Health, was a milestone. It establishes the National Oncological Care Policy. In it, the elements that correspond to the attributions of each management sphere of the Unified Health System (SUS) are shown: health promotion, which consists of the process of empowering the community to improve its quality of life and health, including greater participation in the control of this process; disease prevention, which is the set of actions taken to prevent the occurrence of the disease and its strategies aimed at reducing exposure to risk factors; the diagnosis that results from the process of analysis of the clinical picture and the patient to reach a conclusion;

the treatment that intends to cure or mitigate the impact of the disease and to rehabilitate, and for that it is necessary to identify the issues and needs of the person – the relationship of disorders to relevant factors of the individual and the environment.

Given that the disease is the second cause of death in the world (PAHO / WHO, 2018), the importance of care and the role of the state, from prevention to diagnosis, treatment and death, should be analyzed. Thus, it is registered that Palliative Care has been gaining more space and recognition in Brazilian territory. The goal is to develop the skills needed by health professionals to take care of the suffering of patients and their families facing life-threatening health situations. (ANCP, 2018).

The pioneering work of Cicely Saunders (1967) is noteworthy as it introduced a perspective that differs from traditional health care, which requires understanding that the patient does not only suffer from physical pain (which is treatable with medication and other medical procedures). Thus, the pain observed to treat any pathology gains a new status when it is admitted that its causes come from various factors. Pain is not restricted to biological and chemical aspects, since external

*Corresponding author: **Andrea Frossard Aguiar**

1274, Visconde de Santa Isabel Street, Vila Isabel, Rio de Janeiro, Rio de Janeiro, Brazil.

relations have influence such as beliefs and feelings of the sick.

Understanding the pain and its origin, that is, the causative or interfering factors, is admitting that the actions of the team may benefit the patient and their families, ensuring the non-trivialization of life and the naturalization of death throughout the process, understanding it as part of the natural cycle of life. Recognizing the social dimension as a key to human relationships, the social sciences have an analysis of social pain. Thus, once the disease incapacitates the person, in a mild or severe way, to exercise their sociability, that is, to maintain their social relations, the social pain is aggravated. In general, disability is mainly generated by the physical pain that affects the social life of the being, making it dependent and that can accentuate the expressions of the social problem. Therefore, when considering the social issue as an object of intervention of the social worker in the perspective of Palliative Care, the expression design of the analysis within total pain is social pain. Therefore, the research aims to analyze the strategies of care in Palliative Care, based on the concept of social pain.

Not only is the disease treated, but it includes all the complexity of being, the concept of total pain, defended by Cicely Saunders (1967), is understood as a somatic factor, composed of physical, emotional, social and spiritual aspects. According to the author, "pain requires the same analysis and consideration as a disease in itself" (Apud FROSSARD, 2019, p.39).

Thus, the research's goal is to deepen the knowledge about care strategies in Palliative Care, based on the concept of social pain. It is noteworthy that social pain is not exclusively dealt with by Social Work, just as the other forms of pain that make up total pain are not specifically of a discipline. It is understood that the entire Palliative Care team is responsible for alleviating pain and providing the patient, family and caregivers with adequate treatment, respecting the patient's will.

MATERIALS AND METHOD

The research is based on bibliographic research using the integrative review method. The search was expanded for the period from 2012 to 2019, due to the characteristics of the Brazilian reality that still lacks scientific production in the area of Social Work in Palliative Care.

An active search was performed on the following databases: CAPES Portal – Latin American and Caribbean Health Sciences Literature (Lilacs) and Medline Analysis and Retrieval System (Medline). The following descriptors and their associations in Portuguese were used to search for the articles: Social Work, Palliative Care, Total Pain and Social Pain.

The inclusion criteria defined for the selection of articles were: articles published in Portuguese and full texts that expressed the study on the theme in focus with emphasis on the Social Work approach. Articles that did not address the field of Palliative Care focusing on the social issue were excluded. Data analysis and synthesis were described and classified in order to gather knowledge available in the specialized literature.

The investigation based on documentary research focused on data obtained from public content made available by the

Ministry of Health of Brazil since 1990, the Brazilian National Cancer Institute and the National Academy of Palliative Care (ANCP) with an emphasis on the last ten years.

RESULTS AND DISCUSSION

The word "utopia" comes from the title of Thomas More's philosophical novel of 1516. It means "no place," that is, a place that does not exist in reality. It can refer to the conception of a fair society, without social and economic imbalances, in which all the people have access to good living conditions.

In this sense, it can be said that the field of Palliative Care is not seen as something utopian, but as a feasible reality in the world. For the proposal for Palliative Care assistance in Brazil, there is a lack of initiatives to meet the demands of patients with other pathologies besides cancer. This stems from the recent inclusion of non-curative treatment in the country's legislation, which urges the establishment of strategies for its expansion.

Importantly, the professional practice of the social worker with emphasis on Palliative Care in Brazil was legitimized through Ordinance No. 2,809, of December 7, 2012, which establishes the organization of Palliative Care, to the rear of health care in the Unified Health System (SUS), in which the insertion of the Social Work professional as an integral member of the Palliative Care teams is recommended. (Ministry of Health, 2012, pp. 3-4).

Social Work is an interventionist profession, which proposes an analysis of the social problem and the actions to address it. It can be said that it is the professional who directly interferes with the expressions of the social problem. The social worker, as an integral part of this team, adds quality to the work done, since it makes an "in loco" immersion in the culture, values, history, the reasons that govern the patient's decisions regarding treatment and dimensions of care within the family. Therefore, this professional is qualified to understand the family universe in depth. We look for what family members and patients translate as needs, their sufferings, their knowledge and experiences and the way they organize to resolve adverse situations.

Palliative Care as a Transdisciplinary Field

The Englishwoman Cicely Saunders (1967), when devising and putting into practice the term "total pain" to designate the suffering of cancer patients, provided the foundation for justifying teamwork and thus proving that without cooperative work it is not possible to develop Palliative Care.

In that matter, Palliative Care is understood in the field of transdisciplinarity, considering it has reached a deep stage of interaction between different areas of knowledge, leading them to the constitution of an integrative autonomous knowledge.

Total pain is understood as composed by physical, emotional, spiritual and social pains, the latter being an expression of the social issue, object of intervention of the social worker. In this context, Social Work is inserted as an integral part of the team, working with professionals and patients, focusing on the support network that accompanies them, not restricting

themselves to family members - considering the various forms of community life.

Each of the four dimensions that make up total pain corresponds to the competence of various disciplines. Therefore, it is necessary to value every aspect of the life of those who are suffering. To alleviate total pain is to allow for the patient to enjoy better conditions of living. Palliative care requires assisting the patient adequately, with comfort and consequent quality of life, ensuring their dignity and respecting their decisions.

Souza (2016, p. 6) addresses interdisciplinarity by stating that it represents the “interrelation and cooperation of different fields of knowledge, based on reciprocity, exchange and dialogue between them, in order to develop collectively constructed skills and competences”. Thus, the joint action refers to professionals from different disciplines, the patient who should be heard and respected and their family members, who often accompany them throughout the treatment and experience the negative impacts on their lives due to the aggravation of the patient’s health conditions. Therefore, there is a tripod that, based on exchanges and mediations, can decide on the paths to be taken throughout the treatment: the palliative care team, the patient and family.

In this perspective, one should consider the Palliative Care principle that deals with multi professional care aiming at the extended care needs of patients and family members until after the death (WHO, 2002). Thus, the set of professionals assigned to study, evaluate and implement actions with the family and patient needs to be cohesive, so that decisions can be taken accordingly, seeking the integrated implementation of the care plan to alleviate the distress of those being assisted.

Article 4 of Chapter II of the Statute of the National Association of Palliative Care – Brazil (2018) which provides on “Definitions and corporate purpose” of Palliative Care reads:

II - are practiced by multidisciplinary and interdisciplinary teams that may include health professionals (encompasses, among others, the following professions: Biomedicine, Biological Sciences, Physical Education, Nursing, Pharmacy, Physiotherapy, Speech Therapy, Medicine, Nutrition, Dentistry, Psychology, Social Work and Occupational Therapy, Spiritual Assistants, Lawyers and Volunteers).

In the aforementioned article, the disciplines that make up the set of professions that integrate palliative care are listed.

Acting in a transdisciplinary field, it appears that professionals have introduced effective exchange between specialized knowledge (multiprofessional) and the search for collaboration between different disciplines (interprofessional) in order to provide adequate assistance to situations that occur in the daily routine of health units.

The Multiple Dimensions Present in the Concept of Need and Intervention in Social Pain

According to the Brazilian Institute of Geography and Statistics (IBGE), in data collected and analyzed by the Synthesis of Social Indicators (SIS), currently in Brazil there are 13.5 million people in extreme poverty, that is, under R\$ 145, 00 per month per capita. This means that the number of Brazilians in extreme poverty equaled the total population of

countries such as Bolivia, Belgium, Cuba, Greece and Portugal (IBGE, 2019).

The social data reported above show that a large part of the Brazilian population suffers to gain access to basic services, such as health and information, which guarantee disease prevention through other initiatives.

Palliative Care in Oncology has the goal of offering comfort measures to patients who, without the possibility of cure, experience the multiple phenomena of the social issue. From the palliative team, the social worker is the professional who seeks to learn about the daily lives of patients and their families, that is, their family dynamics. Therefore, the social worker seeks to analyze the different nuances that negatively affect the quality of life of patients.

At the Palliative Care in Oncology, the global understanding of the patient's treatment history provides the apprehension of the expressions of the social issue that predominates at a given moment. Thus, from the joint intervention with the other Palliative Care in total pain and, specifically, in social pain, the social worker will be able to formulate strategies and accurately refer to the services of the care network when necessary.

According to Frossard (2018, p. 4):

Social pain is derived from multiple sources, including lack of adequate food or clothing, housing, stigma and discrimination by disease, extreme poverty, sexism, racism or religious prejudice. In addition, countless families face financial difficulties due to the serious illness of one of its members.

Necessity means essential, something that cannot lack. In this space, it concerns the need for physical survival, that is, many patients and family members undergoing cancer treatment experience an exhausting daily life due to the consequences of the reduced family budget.

Social pain comes from the individual’s relations with the outside world, intensifying at a moment of particular distress. In the context of Palliative Oncology Care, there is an earlier aggravation that refers to the more aggressive and recurrently prolonged treatments, such as the various chemotherapy and radiotherapy sessions that ended up not being effective. As a result, both the patient and their companion during this journey arrive fragile to Palliative Care services.

It should be remembered that the family affected by the burden of caregiving tasks can lead to a lack of effective patient support during treatment. In this sense, the social worker in family management should not have an ideal family as a model, but rather as a real family, with different problems and different arrangements. Therefore, the professional should have a broad notion, from their different compositions, taking into account that not all patients have family ties, either because they do not have them or have broken them before becoming ill. Therefore, friends may be present, enabling equal support for those with the family by their side.

The social worker inserted in the context of Palliative Oncology Care who recognizes the financial situation of the patient and their families through socioeconomic study (part of the social study) will have data to analyze and elaborate their action program and guide them to access to public policies according to their needs.

When a cancer patient is in Palliative Care, the financial costs for them and their support network have no definite end date due to the extent of the treatment that ends in the concreteness of life's finitude, e.g., treatment can be costly if the patient does not do their home treatment (homecare) and needs access to the Palliative Care unit. In this case, you should consider the place where the patient resides, because depending on the distance between their home and the hospital there will be an increase in expenses.

In this direction, some questions need to be answered such as: How will access to the service be made possible? How many public transport fares will be required? Will the patient have food to eat along the way? Will they have the help of a family member or friend? If so, transportation and food costs increase.

According to the World Health Organization (2016, p. 54), Palliative Care "should minimize social distress by providing food baskets, housing assistance and efforts to combat stigmatization and discrimination".

It is believed that the guarantee of rights should be promoted by the state, offering social welfare through public policies. For Mioto, Campos and Carloto (2015, p. 80) it should be recognized that "interrelations between state and family mean understanding the movement of forces of social interests and also the established conceptions that underlie public policies or their absence". Therefore, if the Brazilian social context is calamitous, the State's omission in the field of social protection becomes evident, opening a gap for that a large part of the population to suffer the consequences of being included in the condition of intensified vulnerability.

The various Brazilian entities such as the Brazilian Association of Lymphoma and Leukemia (ABRALE) have information on the rights of cancer patients, aiming to guide and inform cancer patients and its support network to facilitate access to different social resources. Thus, based on the information available in educational materials distributed to the population by entities linked to the cancer field and specific legislation, some rights of cancer patients, such as free public transport, will benefit or soften the precarious financial situation of those who are at a situation of heightened vulnerability.

CONCLUSION

Considering poverty as a health risk factor (STRINGHINI, 2017), Frossard (2019, p. 44) argues that "the necessary reduction in poverty levels to contain mortality is beyond the scope of individual actions because its resolution is complex, since it depends the policies and effective government actions. Thus, the social worker should act make feasible social rights and refer patients to the necessary equipment and services, according to what was identified through the social study, as well as to observe the adequate sharing of information with the other members in the Palliative Care team.

The social worker should act towards make feasible social rights and refer patients to the necessary equipment and services, according to what was identified through the social study, and share information appropriately with the team as well.

As the regulation of Palliative Care ensured by the Unified Health System as part of the Brazilian system of continuous comprehensive care is very recent, the policies on the subject

are not consolidated. However, in some cases, as for cancer patients and their families, there are benefits. Thus, it can be inferred that the greater the access to public policies, the smaller the financial impacts will be and, consequently, the less suffering from the social dimension of pain.

In conclusion, the impact of the worsening of the patient's health conditions also affects the family whose centrality is a priority in health policy in Brazil.

Conflict of Interest Statement

There are no conflicts of interest.

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