

The social representations of medical clinic nurses on oncology palliative care: a procedural approach

Abstract

Introduction: this study refers to a research process about the social representation of nurses on oncological palliative care.

Objectives: to analyze and describe the social representations of nurses on the patient in oncological palliative care and to discuss the implications of these findings in these patients' daily assistance.

Materials and methods: A qualitative study, based on the Social Representations Theory, conducted with 15 nurses that worked in the Clinical Service through semi-structured interviews, analyzed through the thematic content analysis.

Results and discussion: The data show that the content of the social representation of those nurses was predominantly negative, through the terms death, finitude, terminal illness, pain and suffering that are against to the philosophy of palliative care.

Conclusion: training activities in the area and expand of the discussion on the topic are required in an attempt to promote improvements in the care provided to those patients.

Keywords: nursing, neoplasms, palliative care

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Introduction

Cancer is a serious public health problem in developed and developing countries.¹ In 2012, there were 14.1 million new cases of cancer and a total of 8.2 million cancer deaths worldwide. In Brazil, excluding cases of non-melanoma skin, about 576 new cases of cancer are expected for the year 2014 and 2015, with 204,000 new cases for males and 190,000 for females. Cancers with a higher incidence for males are cancers of the prostate, lung, colon and rectum, stomach and oral cavity. Already for the female, are cancers of breast, colon and rectum, cervix, lung and thyroid gland.² Globalization and industrialization have generated changes in societies, with redefinitions of living standards, with standardization of working conditions, consumption and nutrition. At the same time, there were changes in world demography, with a reduction in mortality and birth rates, as well as an increase in life expectancy and population aging. This global reorganization has led to changes in health-disease processes, with decreasing rates of infectious diseases and increased rates of chronic degenerative diseases, especially cardiovascular diseases and cancer.¹ Cancer today is a disease with potential for cure when access to early diagnosis is available and treatment occurs in specialized centers, increasing survival. However, even with the progress observed in the last decades, there is still the possibility of not being cured.³

Palliative care comprises the assistance of a multidisciplinary team

aimed at improving the quality of life of the patient and his/her family in the face of a life-threatening pathology through the prevention and relief of suffering, early identification, evaluation and treatment of pain and other physical, social, psychological and spiritual symptoms.⁴

This mode of care should come into play when the pathology presents advanced stage, or evolution of this condition even during curative treatment, for the management of symptoms with difficult control and psychosocial aspects. It is important to stress that the end of curative therapy does not mean the end of an active treatment, but rather changes in treatment goals.⁵

During the therapeutic process, the professional category that remains in contact with the clients is nursing, and their care is not restricted to merely technical actions, but rather, they seek to contemplate the various characteristics inherent to the human being.⁶ However, through a simple empirical observation of daily work in many health care institutions, it can be seen that the philosophy of this modality of treatment is not always fully applied to persons deliberate for palliative care by the medical staff.

In view of the panel presented, we delimit as object of this study the social representations of the nurses of medical clinic on palliative oncology care. The general objective of this study is:

- i. Analyze the social representations of nurses of non-specialized medical clinic about the patient in oncology palliative care.

The specific objectives are:

- i. Describe the social representations of the medical clinic nurses on the cancer patient in palliative care.
- ii. To discuss the repercussions of these findings on the daily care of cancer patients in palliative care.

This study justifies, therefore, cancer mortality in 2004 represented 13.7% of all deaths recorded in the country and one of the factors that strongly influence survival is the extent of the disease at the time of diagnosis.⁷ Early diagnosis is of great relevance, since late diagnosis is associated with advanced disease, reduction of survival and high rates of mortality and morbidity.⁸ In cases where the cancer enters an advanced stage, or evolves to this condition even during palliative treatment, the palliative approach must be taken into account in the care of the symptoms of difficult control and some psychosocial aspects associated with the disease. Palliative care should be applied to all patients with chronic-degenerative diseases with advanced disease, aiming at better symptom control and quality survival.⁹ Brazilian hospitals, especially the medical clinic, are in constant contact with the oncological patient, and this patient is often classified as having no therapeutic possibilities for cure. The nurse, a health professional, who is in contact with this patient 24 hours a day, develops nursing care, which must be humanized and focused on the patient-family binomial, providing quality of life for these patients.

Considering that the Theory of Social Representations allows the understanding of symbolic constructions, practices and attitudes,¹⁰ the identification of the Social Representations of the professionals who work in this field of palliative care will allow a broader debate and a better understanding of the complex established in this context.

Materials and methods

The present study was a qualitative field research with descriptive and analytical character based on the procedural approach of Theory of Social Representations. This Theory has been widely used in qualitative research in the field of health, appropriated by researchers to proceed with the analysis of specific objects of the professional daily life since this field has an intrinsic relation with the social and symbolic sphere. In this area of knowledge, the subjects involved in the care process (health professionals or clients) are understood as actors who construct and negotiate social arrangements through their experiences and representations that emerge from everyday relationships.¹⁰

Study fields

This study had as a research site the non-specialized medical clinic wards of a university hospital in the state of Rio de Janeiro. The university hospital is located in the North Zone of the city of Rio de Janeiro and promotes high and medium technological complexity assistance to inpatients and outpatient follow-up.

Study participants

For this study, 15 nurses who have been working for more than one year in these medical clinic sectors who agreed to participate in the study and who extend their care to oncological patients out of current therapeutic possibilities are addressed.

Data collection

As a data collection instrument, the semi-structured interview was used.

Data analysis

In order to analyze the data, the thematic content analysis technique was used, consisting of “a set of communication analysis techniques, aiming to obtain, through systematic and objective procedures for describing the content of the messages, indicators (quantitative or not) that allow the inference of knowledge regarding the conditions of production/reception (inferred variables) of these images”.¹¹ This analysis was carried out in three phases: the pre-analysis, the exploitation of the material and the treatment of the data.

Ethical and legal aspects

Ethical and legal aspects were observed in compliance with Resolution 466/2012 of the National Health Council (CNS). The project was submitted to the Ethics and Research Committee of the Pedro Ernesto University Hospital of the State University of Rio de Janeiro and approved by CAAE Opinion 25535013.3.0000.5259 issued on February 20, 2014.

Results

Initially, the socio-demographic profile of the interviewees was traced, a necessary step to present to the readers an overview of the characteristics of the subjects. In addition, these data can facilitate the understanding of the speeches and the apprehension of the social representations of this group. The data indicate that 60% of the group consisted of individuals between the ages of 22 and 30 years, 20% were individuals between 31 and 35 years and 20% were between 41 and 45 years. Only 6.66% of the interviewees were male, compared to 93.33% female. It was also identified that 93.33% of the interviewees had only 01 to 05 years of training, and 6.66% of those interviewed who had between 06 and 15 years of training. In addition, 80% of the interviewees did not have specific training in the oncology area, and 20% had oncology training. In relation to the qualitative results derived from the content analysis, 522 recording units (RU) were found, distributed in 47 subjects and grouped in 04 categories that establish the relationship of professionals interviewed with patients in palliative care and their relatives, and the organization reflections of the study participants, which will be presented and discussed in the following paragraphs.

Palliative care

This category consists of 119 UR (22.84% of the total UR) and with 07 subjects. The word palliative comes from the Latin *pallium*, which means mantle, cloak. From this meaning, one can perceive the essence of palliative care, which includes alleviating the symptoms, pain and suffering of patients with chronic-degenerative diseases in their final phase, aiming to promote quality of life.¹² Thus, the focus of care and treatment ceases to be the cure of the disease, and is the relief of symptoms and the improvement of the quality of life, as long as there is life, without prolonging it or delaying it. To talk about palliative care, it is necessary to think first of the one who will be the target of all care and attention: the patient. The patient, with chronic degenerative disease, in the case of this work, cancer, considered as out of current therapeutic possibilities, suffering the impositions of illness, pain, discomfort, other physical symptoms, besides the emotional, social and psychological symptoms, which has a family that also suffers, going through the emotional tensions of knowing “the gates of death” or, often, not knowing what is happening with his own body. In addition, he is often hospitalized with no power of decision over his body and procedures to be performed. Emotional and psychological conflicts are great in this period, besides the

annoyances and physical sufferings. The professional perceives itself before these situations, often without knowledge and means to assist the patient in these moments; besides, there is still the family to be considered, who suffers together, and also needs to be cared for and treated.

These nuances can be evidenced in the fragments below

- i. Is a person who is very debilitated, feels many pains (line 39-40, interview 14).
- ii. This makes the person always pushing the nurse (line 40-41, interview 14).

The topic “comfort promotion” was cited in 12 interviews, which shows the importance given by the interviewees to the promotion of comfort in palliative care. Within palliative care, promoting comfort is an essential care to provide quality of life at the end of life. The promotion of comfort is not a specific care; is connected to all care. Provide relief from pain, relief from uncomfortable symptoms, decrease discomfort, remedy doubts, try to assist the patient in their difficulties and sorrows, assisting in all aspects, physical, psychological, emotional, social, with multiprofessional team interaction, will increase the levels of patient comfort. Simple aspects such as change of decubitus, a clean bed with well-arranged sheets and changed, the patient correctly sanitized with their dressings done, generate comfort to it. Nursing is a great partner of the patient right now. Treating the familiar and assisting him in times of difficulty also provides comfort and quality of life. Realizing some patients’ wishes is also a way of providing comfort.

Being the prerogative care of the professional nurse, and the professional nurse present 24 hours with the patient. Studies show that the nursing professional can “assist and support the patient in physical, emotional, social and spiritual changes, identifying their real needs and promoting greater comfort”.¹³ Another important point in assisting patients outside the current therapeutic possibilities is to stay with the family, receiving treatment of quality and comfort.¹⁴ These issues are expressed in the following fragments:

- i. So, we follow prescription medication and perform care and nursing, always aiming for comfort, pain relief, mainly think pain relief (line 28-29, interview 15).
- ii. Comfort for the patient, comfort for the family and respect (line 34, interview 02).

Professional approach to palliative care

This category presents 160 UR (30.71% of UR) and 09 subjects. Palliative care is a recent form of care, where the focus is on offering quality of life to the individual, who finds himself without current scientific means of healing. In this case, care will be offered aimed at relieving and reducing symptoms, and promoting quality of life. It is important that this care involves not only the patient but also the family member who accompanies the patient during this troubled period of his or her life. In order for quality care and treatment to occur, it is essential that all health staff be focused and able to treat the patient in palliative care.

The question of the shift from “cure” to “caring” that palliative care represents still finds barriers in the society in which we live. Health professionals are trained to heal, and when this goal is not possible, they feel incapable, defeated in their work; but it is important to remember that in the cycle of life, death is inevitable, and if we are

born, from death we do not escape. Palliative care emerges as a new proposal of care, shifting the focus of healing, to the quality of life, as long as there is life. For most professionals, care for the terminally ill and the family was considered to be unsuccessful medicine and effort. However, patients and families have rights and needs that must be met, regardless of their cure or absence of cure.¹⁵

The professionals highlighted this feeling of failure in the following discursive segments:

- i. You will do a job that is sometimes very tiring and does not have the expected return (line 30-31, interview 04).
- ii. You will work with care and you will see that there will not be a return (line 20-21, interview 04).

The modality of palliative care is a modality of care described by some professionals as a difficult modality, because it is the care provided to patients who are “dying” or “at the end of life”. Many have difficulties in dealing with these patients, and end up putting themselves in the customer’s place, trying to perceive their pains, anguishes, sufferings; they also put themselves in the place of the family, thinking what it would be like if this happened to their loved one.

The proximity of death leads people to reflections and questions about their lives and choices, expressed in the following discursive productions:

- i. I think you have to put yourself in his place, or in the place of any relative who is seeing him there (line 24-25, interview 06).
- ii. But there are cases where there is no way we cannot remember, not think (line 27, interview 09).

The family has active participation and is involved in the philosophy of palliative care. The study points out that “dealing with the dying process is dealing with suffering, not only the patient’s physical and exclusive pain, but also the pain of the losses experienced by patients and their relatives”.¹⁶ The importance of interdisciplinarity in patient care in palliative care was also discussed. The patient in palliative care is affected by a variety of physical, psychological, emotional and social symptoms, thus requiring the support and care of the entire team. Each professional should contribute with his specialty, but the discussions between knowledge are important to define the best care and treatment to be offered to the patient. The exchange and union of professionals can only bring gains for the care of this patient. In this perspective, it is emphasized that “palliative care presupposes the action of a multiprofessional team, since the proposal consists in caring for the individual in all aspects: physical, mental, spiritual and social. The terminal patient should be fully assisted, and this requires complementation of knowledge, sharing responsibilities, where different demands are solved together”.¹⁷ Palliative care names the actions of a multiprofessional team in the care of patients out of current therapeutic possibilities.¹⁷

The subjects reveal this multidisciplinary approach when they reveal that

- i. Have a communication with the multidisciplinary team, the physician who is there responding, the technicians, the nurse on call, the resident who will be there taking care of, nursing resident, nutritionist, nutrition, if the patient has an enteral, parenteral diet, or even on a zero diet (line 36-39, interview 02).

- ii. The staff is also a whole. No one works alone (line 40 - interview 02).
- iii. Seeking the knowledge and drawing a plan for him, along with the whole team (line 56-57, interview 12).

Nursing care in palliative care

The category was structured with 152 UR (29.17%) and 11 themes and emphasizes nursing care in the form of palliative care. Nursing is the category to spend more time with the client on their end of life than any other professional. Nursing care in palliative care aims to “provide comfort, act and react adequately to the situation of death with the patient, family and with himself; is to promote the personal growth of the patient, family and self, is to value suffering and achievements, to empower the other with his or her care and to be empowered by care, to strive to preserve physical, moral, emotional and spiritual integrity, is connect and bond and help the other and yourself to find meaning in situations. Caring for palliative nursing is to provide symptom relief, to be flexible, to have care goals, to advocate for the patient and to recognize him as a unique human being”.¹⁸

The relevance attributed to care is perceived when in all interviews, at some point, this subject is addressed. Care is the main part of nursing work, it is the professional’s own performance, and it has great weight in patient care. In palliative care, where patients usually find themselves weak, weak, with physical and emotional pain, care becomes very present, both by their presence and by their absence.

The interviewees cite a lot of “caring with dignity”, a way to offer quality care, thus helping to reduce or at least comfort the client.

- i. Do our service with dignity (line 21-22, interview 03).
- ii. I try to do my best (line 23, interview 08).
- iii. You are taking proper care (line 26-27, interview 12).

Regarding the family involvement in palliative care, it is noticed through the statements of the interviewees, the importance of extending care to the patient’s relative in palliative care. When talking about the moment the palliative patient is going through, it is of great importance to support and welcome the family. However, the family also suffers along with the patient, and needs to be taken care of by the team, to move with a little more ease in this troubled period. It is of great relevance to bring the family to the care network, because in addition to the patient needs the family support, the family will also feel supported, welcomed in their suffering.¹⁹

- i. Not only the patient who has to be treated, the family also has to be treated (line 38, interview 01).
- ii. Try to understand that family (line 53, interview 01).

Pain is a distressing physical, psychological, and emotional symptom very present in cancer in general, and is usually very large in terminal cancers. It varies from person to person, but undoubtedly brings much suffering. In palliative care, one of the main goals is pain relief and control, and correct analgesia. It is essential that nursing assess the patient’s pain levels, and together with medical prescriptions and medical staff, perform the correct analgesia for effective pain control of the client. Pain “is a unique and individual experience, modified by the prior knowledge of an injury that may be existing or presumed, that is, in any situation the pain is what the patient refers and describes”.²⁰

- i. It is not normal for him to feel pain and nobody likes to feel pain” (line 47, interview 06).
- ii. How is his pain” (line 44, interview 06).

Existing barriers to adequate pain management and control are related to patients’ non-adherence to treatment, reluctance of doctors to prescribe opioids and the belief that pain is inevitable, widespread in hospital practice; in addition, there is also an academic training related to the area of pain.²⁰ The following statements evidence the reports regarding pain relief.

- i. How are you going to reduce the pain of this patient, how is his pain, is it intense, is it acute” (line 43-44, interview 12).
- ii. Decrease the maximum pain so that she is quiet” (line 39, interview 07).

Humanization

The category is composed of 90 UR (17.27% of UR) and 18 themes. Humanization is the point where it is necessary to increase the degree of responsibilities of the actors and constituents of the SUS network in health care and changes in the culture of attention to users and management of the work process. Bring value to health as a standard is to make a link with users, thus guaranteeing the right to users and their families, encouraging them to become protagonists of the health system through social control, as well as providing decent work conditions for professionals to exercise their actions with excellence and to participate as co-managers of their work process.²¹ Bringing humanization into the context of palliative care, we realize the importance of guaranteeing quality health to patients outside current therapeutic possibilities and their families. Stimulating patients to be protagonists of their own care, even those most debilitated, is part of the humanization of care, and bringing the family to the care is essential to provide comfort to the terminal phase of the patient in palliative care.

It is impossible to speak truly about palliative care and not to relate to the feelings that surround the various factors involved in care, and the feelings of family members and patients. It is complex to approach everyone, because many are the actors involved in palliative care, but the main ones mentioned in the interviewees’ speeches are empathy, fear, tranquility, sadness, worry, help. It is relevant that human relationships are based on empathy and compassion, these characteristics being the main characteristics expected of caregivers,²² a fact highlighted in the speech of the study participants:

- i. I use empathy, try to put myself, put myself in the other’s place (line 27, interview 02).
- ii. I feel very sorry for the patient (line 26, interview 02).
- iii. My feeling is thus of how much more can I do for him (line 35-36, interview 12).

To offer quality care, not only in palliative care but in any area of care, it is necessary to look at the patient in a special way, in a holistic way, perceiving their physical, psychological, emotional, social, and biological dimensions. The patient is not only an organ with a tumor, but a living being rich in complexity of feelings, with a life, thoughts and right to choices. Palliative care is effective and helps in this moment, because it reduces suffering, facilitating the relationship between those involved and promoting humanized care through a

holistic view of the patient, as well as his own name says pallium, mantle, cover, protector.²³

On this holistic essence, the professionals spoke that:

- i. Patient is a whole (line 40, interview 02).
- ii. Because that there is a person, it is a life (line 50, interview 02).

Although palliative care has as its philosophy the search for relief of symptoms and promotion of quality of life, the suffering is still very associated with it by the interviewees, which may show a failure to apply the principles of palliative care. When the patient suffers, he also suffers the family member, because he cannot help at that moment, and suffers the health team, because often his actions end up not being enough to cure the patient's symptoms, generating worries and loss of quality of life for that client. Pain is a very present symptom and directly related to the suffering of the patient. Also in this direction, it should be emphasized that palliative care is an approach that improves the quality of life of patients and families facing associated problems with life-threatening illnesses, through the prevention and relief of suffering, by means of early identification, correct assessment and treatment of pain and other physical, psychosocial and spiritual problems.²⁴

This data can be identified when subjects reported that:

- i. Because he is suffering, has no therapeutic possibility, that I will leave the person in pain (line 46-47, interview 02).
- ii. Some suffer a lot (line 23, interview 05).

Conclusion

At the end of this study, it is identified that the social representation of the nurses addressed in this research is, mostly, negative. Palliative care for respondents is linked to terms such as “death, finitude, terminality, beyond therapeutic possibilities”. Social representations are fruits of the practical experience of the individual, which shows that the experiences of these professionals with patients in palliative care are linked, especially to death. However, it is of great relevance not to identify the patient in palliative care only as “the one who is going to die”, but as a living person who deserves to have quality of life and dignity in this period, regardless of the time remaining. Another negative social representation associated with palliative care by the interviewed population was pain and suffering, revealing that these individuals have not contemplated the basic principles of palliative care, which are relief and decrease of pain and other distressing symptoms. Despite the diversity of current medications and therapies, pain is still a problem for all healthcare staff, which deals with palliative care, since a patient with pain will not have quality of life.

Considering that social representations can be determinants of practices, these social representations of the investigated group, of a negative nature, lead to some of the positions found in the research, such as distance and feeling of overload. In addition, we also addressed the emotional and technical lack of preparation for palliative care clients, which generates wear and difficulty for professionals in the care of this patient.

Palliative care is still a differentiated form of care, something recent for nursing and the entire health team, despite all its history. The study and the search for knowledge are of great relevance to the practice, since the theory provides foundation for quality care. The

correct identification and application of the principles in palliative care by the health team generates comfort and quality of life for the patient in palliative care.

Some nurses raised the issue that nursing care in palliative care is similar to the care of other curable patients. Although palliative care is understood as a philosophy to be applied at a time when the patient has no possibility of cure, and the treatment aims at other goals, such as quality of life and no longer cure it, nursing care remains the same. This patient still needs to have his hygiene respected, his medications administered at the right time, his food is supplied, regardless of the environment, in other words, the nursing care to this patient should continue, only the goal of treatment that will change focus, becoming comfort and quality of life. Nursing care is essential for the comfort of any patient, and the patient out of current therapeutic possibilities is no different. However, nursing should be more attentive to therapeutic communication, always aiming to offer quality care to this client. Posture, conversation, a smile, a word of comfort or even an understandable silence are attitudes that show the patient that he is not alone, that there is someone watching over him. Extended family care is also of great importance, since it suffers together, deserving and should be the focus of nursing care.

The integration of the different knowledge, that is, the union of the health team, each one within its discipline, but all seeking the correct implementation of palliative care also generates means to qualify the treatment of patients in palliative care. It is therefore suggested that new studies and a broadening of the debate on the subject be developed in order to improve professional practices with a consequent real implementation of this philosophy of care in the institution under investigation.

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Conflict of interest

The author declares no conflict of interest.

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