

# PALLIATIVE CARE GUIDELINES FOR PATIENTS UNDERGOING HEMATOPOIETIC STEM CELL TRANSPLANTATION\*

Vivian Maria Reksua<sup>1</sup>, Maria Cristina Paganini<sup>2</sup>

<sup>1</sup>Nurse. Master in Nursing. Nurse at the Service of Bone Marrow Transplantation of Hospital de Clínicas da Universidade Federal do Paraná. Curitiba, PR, Brazil.

<sup>2</sup>Nurse. PhD in Nursing. Professor at Universidade Tuiuti do Paraná. Curitiba, PR, Brazil.

**ABSTRACT:** Qualitative study aimed to propose palliative care guidelines for patients undergoing hematopoietic stem cell transplantation. The setting was a teaching hospital in Curitiba, state of Paraná. The study was conducted in 2014 in two stages: the first, exploratory stage, with semi-structured interviews with 12 nurses. Three topics emerged from content analysis: 1) Perception of palliative care in the workplace; 2) Sense assigned to palliative care; 3) Professional-family interaction in palliative care. In the second stage palliative care guidelines were proposed and approved in meetings with nurses. The definition of palliative care guidelines may facilitate and improve the palliative care delivered by multidisciplinary teams, with a positive impact on the quality of life of patients with a terminal disease and their families.

**DESCRIPTORS:** Palliative care; hematopoietic stem cell transplantation; Nursing; Guide to clinical practice.

## DIRETRIZES PARA CUIDADOS PALIATIVOS PRESTADOS A PACIENTES SUBMETIDOS A TRANSPLANTE DE CÉLULAS TRONCO HEMATOPOÉTICAS

**RESUMO:** Estudo de abordagem qualitativa como o objetivo de propor diretrizes de cuidados paliativos aos pacientes submetidos a transplante de células tronco hematopoéticas. O cenário foi um hospital de ensino em Curitiba, estado do Paraná. O estudo foi desenvolvido em 2014 em duas fases: a primeira, exploratória, com entrevistas semiestruturadas com 12 enfermeiros. Da análise de conteúdo emergiram três temas: 1) Percepção sobre a experiência do cuidado paliativo no trabalho; 2) Sentido atribuído ao cuidado paliativo; 3) Interação profissional-família em cuidado paliativo. Na segunda fase foram realizados encontros com os enfermeiros, para propor e aprovar diretrizes aos cuidados paliativos. A definição de diretrizes pode facilitar e beneficiar a prática do cuidado, junto ao paciente, família e equipe multiprofissional, no final de vida e no enfrentamento da morte.

**DESCRIPTORIOS:** Cuidado paliativo; Transplante de células tronco hematopoéticas; Enfermagem; Guia de prática clínica.

## DIRECTRICES PARA CUIDADOS PALIATIVOS PRESTADOS A PACIENTES SOMETIDOS A TRASPLANTE DE CÉLULAS MADRE HEMATOPOYÉTICAS

**RESUMO:** Estudio de abordaje cualitativo cuya finalidad fue proponer directrices de cuidados paliativos a los pacientes sometidos a trasplante de células madre hematopoyéticas. El escenario fue un hospital de enseñanza en Curitiba, estado de Paraná. El estudio fue desarrollado en 2014 en dos fases: la primera, exploratoria, con entrevistas semiestruturadas con 12 enfermeros. Del análisis de contenido resultaron tres temas: 1) Percepción sobre la experiencia del cuidado paliativo en el trabajo; 2) Sentido del cuidado paliativo; 3) Interacción profesional-familia en cuidado paliativo. En la segunda fase, fueron realizados encuentros con los enfermeros para proponer y aprobar directrices a los cuidados paliativos. La definición de directrices puede facilitar y beneficiar la práctica del cuidado, con paciente, familia y equipo multiprofesional, en el fin de vida y en el afrontamiento de la muerte.

**DESCRIPTORIOS:** Cuidado paliativo; Trasplante de células madre hematopoyéticas; Enfermería; Guía de práctica clínica.

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### Corresponding author:

Vivian Maria Reksua  
Hospital de Clínicas da Universidade Federal do Paraná  
Tv Capitão Clementino Paraná, 130, ap 71 - 80620-190 - Curitiba, PR, Brasil  
E-mail: vreksua@sms.curitiba.pr.gov.br

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## INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) is a “therapeutic procedure consisting in intravenous infusion of hematopoietic stem cells (HSC) to reestablish marrow function”<sup>(1:472)</sup>. The purpose of the treatment is to graft healthy hematopoietic progenitor cells to correct a quantitative or qualitative defect of the bone marrow<sup>(2)</sup>.

The HSCT is described as a highly specialized procedure, performed in centers of excellence for the treatment of patients with diseases that are often incurable. Thus, taking care of the patient is a complex task also from an emotional point of view. A major difficulty faced by HSCT professionals is dealing with situations of inevitable worsening of patients' health status. These nursing professionals are focused on cure, in the sense of restoring health. However, when cure is not possible, palliative care becomes the total focus of care, to provide comfort and relief of suffering<sup>(3)</sup>.

So, the risk of death associated to HSC should be considered in care, as well as support to nurses, who may feel frustrated and vulnerable, being unable to deal with death. As a result, these professionals avoid talking about the subject, although they perform their duties in wards with patients with serious illnesses. They are probably afraid of losing control of the situation, which can have very serious consequences<sup>(4)</sup>.

Regardless of whether or not the patient has an incurable disease, the nurse's caring role includes comprehensive care to the patient, family members and responsibilities towards the multidisciplinary team. The present study addresses those situations where curative possibilities have been exhausted and palliative care is required. In such situations, caring, rather than curing, becomes the focus (comprehensive health care)<sup>(5)</sup>.

According to the World Health Organization<sup>(6)</sup>, palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

Some principles of palliative care: provides relief from pain and other distressing symptoms;

affirms life and regards death as a normal process; intends neither to hasten nor to postpone death; integrate the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the families during the patient's illness and in their bereavement; offers a multidisciplinary approach to meet the needs of patients and their families; improves quality of life and positively influences the course of the disease<sup>(7)</sup>.

Under this perspective, the present study aims to propose palliative care guidelines for patients undergoing hematopoietic stem cell transplantation.

## METHOD

The study was conducted in a public teaching hospital, at the Hematopoietic Stem Cell Transplantation Unit, in the city of Curitiba, state of Paraná, throughout 2014 up to January 2015.

It was an intervention study in a two-stage design as follows: 1) qualitative exploratory research involving 12 nurses of a HSCT by semi-structured interviews, and by criterion of information saturation, subjected to content analysis; 2) workshops were conducted with the nurses of the unit to elaborate the proposal of palliative care guidelines.

Interview data were collected in the inpatient unit. The participants were nurses employed in the hospital who performed their professional duties in the HSCT unit. The nurses who refused to participate in the study or who were on a sick leave or absent for another reason were excluded. All respondents signed the Free Informed Consent Form.

All interviews were coded with letter E followed by a serial number: E1...E12. Analysis of the research data was based on the description of the content of the written messages, and Bardin's content analysis was used as a reference for transcript analysis<sup>(8)</sup>.

This study was approved by the Research Ethics Committee of Universidade Federal do Paraná under no 627.484, according to resolution of Brazil's National Health Council. Confidentiality was ensured to the participants, and they had the right to withdraw from the study at any time.

## RESULTS

All respondents were female individuals, aged 28-62 years and with professional training of 5-29 years.

The respondents' perceptions of palliative care were based on their professional experience, and three topics were highlighted, based on thematic analysis (detail, consistency and relevance). The highlighted topics were Perceptions of the experience with palliative care in the workplace; Sense assigned to palliative care; and professional-family interaction in palliative care.

The topics originated from the categories allowed formal structured content analysis, which reflect significant and reliable results. Inferences and interpretations can be proposed based on these results. The topics are as follows.

### Perceptions of the experience with palliative care in the workplace

According to the respondents, working at the HSCT unit is both a challenge (the overcoming the distress and frustration for caring for dying patients) and achievement (the opportunity of working in a unit that uses advanced technology).

*Sometimes, there is graft rejection after one, two or even three attempts of transplantation, and the patient evolves to death... and that is it (E1)*

*We feel very sorry for the patient... it is hard to care for a patient that will not survive. We did not expect it to be this way (E11)*

Furthermore, a clear definition of palliative care is necessary to ensure an effective integrated multidisciplinary team. Some nurses report that it is hard to achieve such integration among the members and that there is not a clear definition of when and whether the patient is under palliative care.

*There is a need for greater clarity on when a patient requires palliative care. And this should not take too long to occur. (E3)*

In addition, the way nurses respond to job-related stressful situations depends on their personality, which is observed in the statements, especially when the respondents mention the relationship with patients in palliative care, as shown in the following transcript:

*Sometimes we avoid telling the truth... and tell the patient that blood pressure is good, knowing that he/she is seriously ill, and blood pressure matters*

*the least now (E1)*

In most statements, the nurses explain the change of paradigm regarding palliative care to patients undergoing hematopoietic stem cell transplantation HSCT, and talk about their daily routines.

*I know that we can support and comfort the relatives and mitigate the suffering of patients. We are responsible for the entire process of care... and dying should be considered a normal process (E2)*

### Sense assigned to palliative care

Palliative care has two aspects: on the one hand, the ideal of not shortening life and on the other hand, the vision of not prolonging suffering. Therefore, it is necessary to provide quality of life in death. The respondents expressed their certainty about this need, as follows:

*I believe that palliative care involves than the ordinary hospital care procedures such as tests, medication, and appropriate nutrition, among others. Social and personal issues should also be addressed. (E3)*

However, it is necessary to effectively promote palliative care, because although the nurses have their own views about life and death, they find it difficult to adopt palliative procedures in their daily activities.

*There is no protocol, no understanding of what palliative care is in this unit (E12).*

*I notice that no one has a clear understanding of palliative care here (E2).*

Therefore, the nurses of this unit have to deal with the particular complexity of HSCT, in addition to delivering palliative care, as it can be seen in their statements.

*We do our best, we administer the drugs to the patients according to prescriptions, pain medication, antipyretic medication, etc. we also assist in hygiene, nutrition and hydration, but pain is our greatest concern. (E8)*

However, the administration of palliative care causes discomfort to health professionals, as shown in the following statements.

*Caring for people is something complex, especially when it involves someone facing a very stressful situation, such as serious illnesses and proximity of death. (E9)*

One respondent expresses the wish for changes, for a new perspective in palliative care,

as follows:

*Se eu pensava até pouco tempo que o que se faz aqui em cuidados paliativos estava bom, venho percebendo que precisa melhorar.* (E4)

*Until recently I believed that the palliative care delivered in this unit were appropriate. Now, I think that changes are needed.* (E4)

Palliative care strategies should involve a multidisciplinary team, not only one professional team. This aspect was mentioned by some respondents

*Palliative care should be delivered concomitantly by all the members of the multidisciplinary team.* (E3)

*The entire multidisciplinary team must be involved in palliative care, not only the nurses.* (E12)

### **Professional-family interaction in palliative care**

The nurses who shared their experiences in palliative care stressed the inseparable ties between patients and family members.

*We try to comfort the families to help them cope with a distressful situation because this can be make things even worse for the patient.* (E5)

*Palliative care is comprehensive, particularly because of the prolonged, close contact of the patients' families and the nursing team.* (E9)

Emotional distress resulted from the feeling of hopelessness in the face of very difficult situations involving the families and health professionals.

*These conflicts are very distressful. When we are permanently involved with the patients, walking into the rooms and talking to them, we cannot be indifferent. We feel hopeless.* (E7)

The nurses who delivered palliative care expressed a wide range of feelings that resulted from their prolonged involvement with patients and families.

### **Meetings with nurses aimed to the elaboration of Palliative Care Guidelines**

The workshops with the nurses were held on November 26 and December 03, 2014, in the researched units. These dates were previously arranged, and the meetings lasted approximately 60 minutes. The first meeting was attended by 23 nurses, and there were 19 nurses in the second meeting.

The theoretical-methodological aspects of the research were systematically presented in

the first meeting, as well as the results of the interviews. Then, a proposal of palliative care guidelines was discussed. Overhead projector, oral exposure, among other resources were used in the presentation to obtain better results.

The final proposal consisted in maintaining the model of guidelines presented by the researcher, submitting this proposal to the multidisciplinary team and the unit management. In the second meeting the preliminary proposal was resumed, discussed by the participants and some adjustments were proposed. During the discussion, the nursing management and the researcher announced the establishment of a multidisciplinary committee to expand the guidelines, including components of nursing care, among others, because palliative care comprises other dimensions.

The meetings led the nurses to reflect on the need to improve and reorganize the service, to include palliative care in their routine, in order to adjust to the global tendency of delivering comprehensive health care.

### **DISCUSSION**

The training of health professionals does not contemplate the ability to deal with difficult situations arising from disease progression, recurrence, the impossibility of cure and losses, and the multidisciplinary team that deals with terminally ill patients and their families should be trained to be able to deliver palliative care in these situations<sup>(9)</sup>.

However, nurses often face strict routines and standards and cannot understand palliative care as an approach that contributes to a better quality of life for the patients, which proposes the paradigm of care to the detriment of cure.

Thus, incorporating palliative care in HSCT units is a major challenge, because it is undoubtedly a broad concept that should be introduced in all services, taking into consideration specific knowledge and skills<sup>(10)</sup>.

According to this reasoning, it is possible to perceive palliative care as a philosophy of care and also as a widely structured and organized system of health care, as it expands the traditional approaches to the diagnosis and treatment of illnesses to include targets for the improvement of the quality of life of patients and their families, helping in decision making, providing opportunities for personal growth, and this can

be offered concomitantly with other care<sup>(11)</sup>.

Although it is affirmed that palliative care promote greater quality of life and complement health actions, nurses are often unable to overcome the distress and frustration for caring with dying patients and to deal with their families<sup>(12)</sup>.

Therefore, the ethical issues involved in palliative care should not be ignored. It is essential to recognize the limits of medicine and deliver a treatment that takes into account the risks and benefits involved on a case-by-case basis<sup>(13)</sup>.

This statement proposes the reflection that palliative care is a grim reality. Some nurses that work in HSCT units neglect palliative care because of factors such as time, inability, and even discouragement. It is of utmost importance to recognize the specific needs of the unit and establish strategies for the maintenance of the culture and philosophy of palliative care. Models and programs for palliative care guidelines may redesign strategies of action that involve the institution, the nurses, the families and the patient.

However, qualitative and quantitative aspects must be considered in the proposal of palliative care guidelines, because each unit has its own characteristics, which should be taken into consideration to ensure the delivery of appropriate palliative care.

This study involves palliative philosophy whose motto is adding life to years, not years to life<sup>(6)</sup>. However, concepts related to palliative philosophy are relatively recent in our society, because the implementation of palliative care services in Brazil began only in the 1980's<sup>(14)</sup>, facing resistance from some health professionals who do not feel comfortable in delivering palliative care and avoid it<sup>(15)</sup>.

Despite the movement towards palliative care, there is still much to do to meet specific demands such as those of HSCT procedures and ensure that patients participate in the decision making process regarding the care delivered to them.

On the other hand, HSCT has been carried out in Brazil for thirty years, and despite its benefits, it is considered a complex treatment that involves risks because of some factors that contribute to the increased morbidity and mortality rates in the patients<sup>(16)</sup>.

In this context, palliative care should be

delivered by nurses and the entire nursing team participating in the whole process<sup>(17)</sup>. Moreover, when a guideline is proposed, its gradual incorporation into the HSCT routine is expected. The process involves collective development of the guidelines based on previously selected support material, and should be performed in the workplace to allow for everyone to participate.

The last topic addressed the fragile relationship between family, team and the patient; regardless of the order, this triad is inseparable. The impact of terminal illness and its management are multidimensional for the members of the family that experience these events. Studies reveal that 25% to 85% of terminally ill patients experience symptoms associated to suffering during the last hours or days before their deaths, and their families experience this process with them<sup>(18)</sup>.

When an individual is diagnosed with a serious life-threatening illness and hospitalized, this may generate crises and disruption in their families. When cure is not possible, the palliative care delivered to the patients should address physical, psychosocial and spiritual problems, in addition to the treatment of pain.

The process of caring is not necessarily characterized by the cure or treatment of a given pathology, but also by the support and the attempt to mitigate the suffering of patients and their families<sup>(19)</sup>. In the present study, the nurses corroborate the assertion that the relationship health professional-patient-family is unquestionable and that care should not be delivered to the terminally ill patient only, but to the entire family group, since the family members also need emotional support, as they are preparing themselves to lose a loved one<sup>(18)</sup>.

The higher the status of comfort and confidence, the more positive the experience is, and a relationship of confidence is established between the team and the family members<sup>(20)</sup>. When they report positive experiences the nurses mention the quality of the relationships established.

While acknowledging the efficiency of the teams trained to provide palliative care to patients, such training should be a priority in health care services<sup>(21)</sup>. Nevertheless, in HSCT units the integration between curative care and palliative care must be stressed to improve the quality of the care provided. A guideline that establishes the earliest possible care integrated to other care practices can lead to optimal strategies of care.

## FINAL CONSIDERATIONS

Palliative care can be understood in different ways by the nurses that provide such care in HSCT units. Their experience is built and rebuilt during their professional lives, and their professional lives, in turn, are closely related to the process of cure. These nurses feel frustrated and hopeless when their patients die, because death is seen as a failure, and they were trained to fight it.

The interviews with the nurses demonstrated that the participants consider a palliative care guideline for patients undergoing HSCT to be an indispensable tool for promoting palliative care, as it will make it possible to clarify doubts and scientifically support the actions and strengthen human care.

One limitation of this study concerns the greater scope of the guideline, which is now extended to the multidisciplinary team, persisting even after the completion of the study. Given the lack of research in palliative care in HSTC units, further studies are needed to clarify this issue.

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