

---

## REDEFINING PALLIATIVE CARE AT A SPECIALIZED CARE CENTER: A POSSIBLE REALITY?

Mara Ambrosina de Oliveira Vargas<sup>1</sup>, Janaina Vivan<sup>2</sup>, Rosmari Wittmann Vieira<sup>3</sup>, Joel Rolim Mancia<sup>4</sup>, Flávia Regina Souza Ramos<sup>5</sup>, Sílvia Ferrazzo<sup>6</sup>, Júlia Valéria de Oliveira Vargas Bitencourt<sup>7</sup>

<sup>1</sup> Ph.D. in Nursing Philosophy. Professor, Nursing Department and Graduate Nursing Program (PEN) at Universidade Federal de Santa Catarina (UFSC). Florianópolis, Santa Catarina, Brazil. E-mail: mara@ccs.ufsc.br

<sup>2</sup> Intensive Care Nursing Specialist. Alegre, Rio Grande do Sul, Brazil. E-mail: janavivan@yahoo.com.br

<sup>3</sup> M.Sc. in Bioethics and Palliative Care. Nurse, Center for Palliative Care, Hospital de Clínicas de Porto Alegre. Alegre, Rio Grande do Sul, Brazil. E-mail: rvieira@hcpa.ufrgs.br

<sup>4</sup> Ph.D. in Nursing. Nurse, Porto Alegre Municipal Government. Rio Grande do Sul, Brazil E-mail: joelmancia@uol.com.br.

<sup>5</sup> Ph.D. in Nursing Philosophy. Professor, Nursing Department and PEN/UFSC. CNPq Researcher. Florianópolis, Santa Catarina, Brazil E-mail: flaviar@ccs.ufsc.br

<sup>6</sup> Master's student, PEN/UFSC. Santa Catarina, Brazil. E-mail: silvia.ferrazzo@gmail.com

<sup>7</sup> M.Sc. in Nursing. Professor, Nursing Department, Universidade Federal Fronteira Sul. Chapecó, Santa Catarina, Brazil. E-mail: julia.bitencourt@uffs.edu.br

**ABSTRACT:** A qualitative research with a case study design was undertaken at the Center for Palliative Care, located within the *Hospital de Clínicas de Porto Alegre*, Brazil, aimed at knowing how palliative care is provided to patients at a specialized unit and how the nursing team works with the caregiver's family to continue with comfort and pain relief measures. The project received approval from the Ethics and Research Committee. The data were collected through direct observation and semi-structured interviews with nurses and nursing technicians. The results are presented through the themes: characteristics of the Center for Palliative Care, its team and the initial interaction with patients and their families; and the type of care and the importance of pain management and communication. In conclusion, in this type of work, the role of technology and the attributes of care relationships are redefined, and ethical values like trust and autonomy are emphasized.

**DESCRIPTORS:** Palliative care. Nursing care. Terminally ill. Personal autonomy.

---

## RESSIGNIFICANDO O CUIDADO EM UMA UNIDADE ESPECIALIZADA EM CUIDADOS PALIATIVOS: UMA REALIDADE POSSÍVEL?

**RESUMO:** Pesquisa qualitativa, tipo estudo de caso, realizado no Núcleo de Cuidados Paliativos do Hospital de Clínicas de Porto Alegre, Brasil, com os objetivos de conhecer como é prestado o cuidado paliativo ao paciente em uma unidade especializada e como a equipe de enfermagem atua junto ao cuidador(a)/familiar para a continuação das medidas de conforto e alívio da dor. Projeto aprovado pelo Comitê Ética em Pesquisa. Procedeu-se a coleta dos dados por observação do funcionamento da unidade e entrevista semiestruturada com enfermeiras e técnicas de enfermagem. Os resultados são apresentados por meio das temáticas: características do Núcleo de Cuidados Paliativos, sua equipe e a interação inicial desta com o paciente e familiares; e os modos de cuidar, a importância da abordagem da dor e da comunicação. Conclui-se que neste tipo de serviço é ressignificado o papel da tecnologia e dos atributos das relações de cuidado, enfatizando valores éticos, como a confiança e a autonomia.

**DESCRIPTORIOS:** Cuidados paliativos. Cuidados de enfermagem. Doente terminal. Autonomia pessoal.

---

## REDEFINIENDO EL CUIDADO EN UNA UNIDAD ESPECIALIZADA EN CUIDADOS PALIATIVOS: UNA REALIDAD POSIBLE?

**RESUMEN:** Investigación cualitativa tipo estudio de caso, realizada en el Núcleo de Cuidados Paliativos del Hospital de Clínicas de Porto Alegre, Brasil, cuyo objetivo fue conocer los cuidados paliativos proporcionados al paciente en una unidad especializada y ver la actuación del equipo de enfermería con el cuidador(a) familiar en la continuación de las medidas de comodidad y alivio del dolor. Proyecto aprobado por el Comité de Ética y Pesquisa. Se procedió a recolectar los datos mediante la observación directa y entrevistas semi-estructuradas con enfermeras y asistentes de enfermería. Los resultados se presentan a través de los temas: características del Núcleo de Cuidados Paliativos, equipo e interacción inicial con el paciente y familiares; y formas de cuidado, importancia del manejo del dolor y la comunicación. Se concluye que en este servicio es redefinido el papel de la tecnología y los atributos de las relaciones de cuidado, enfatizando los valores éticos como confianza y autonomía.

**DESCRIPTORIOS:** Cuidados paliativos. Cuidados de enfermería. Enfermo terminal. Autonomía personal.

## INTRODUCTION

Due to increasing concerns with the bad quality of life patients experience during their progressive illness, the Palliative Care (PC) concept was incorporated into the daily work of health services in Brazil.<sup>1</sup>

According to the World Health Organization (WHO), the aim of PC is to reduce the suffering of terminal patients and their relatives, granting them the best possible quality of life and affirming that the dying process is a part of life and should not be denied to the patient at any time.<sup>2</sup>

Palliative medicine neither accelerates nor retards the dying process, but acknowledges death as a natural element of life. In this perspective, support and help should be granted for patients to be able to live as active and creatively as possible until the time of death has come; and for family members to experience the disease of their relative and the mourning process more naturally and without that much suffering.<sup>3</sup>

The PC philosophy differs from curative treatment. The primary notion is to pay attention to the patient instead of the disease. That demands a multiprofessional approach that can encourage and help patients to make the best of what life has to offer each day, treating them respectfully, attending to their needs and accepting them with their values, beliefs and habits.<sup>4</sup>

Few people are truly ready to make the choices that may be necessary at the end of life. These choices are extremely hard and affect all stakeholders, the terminal patient, the relatives, loved ones and health professionals.<sup>5</sup> In that sense, the establishment of a thoughtful and competent relationship among the nursing team, patients and family members is considered fundamental in PC.

These patients need to be hospitalized when the family can no longer take appropriate care of the patients, due to their complete dependence, which will last for an extended period or, in most cases, when the family members cannot bear watching their loved one suffer. Paradoxically, hospitals tend to offer basic care to these patients and their relatives, but ignore their anguish and suffering. They forget that patients are looking for a good, dignified, respectful and painless death. Hence, due to the need for distinguished care, all over the world,

specific places have been created to welcome these patients.<sup>6</sup>

In sum, despite the huge expansion of PC programs in hospitals, not all institutions offer units specialized in this care. In addition, the premise is adopted that health professionals in general are unfamiliar with and do not apply this work philosophy and that health institutions do not provide a physical structure to include a Palliative Care Center (NCP). Therefore, the aim in this study was to get to know how PC is delivered to patients at a unit specialized in this care and how the nursing team works with the caregiver/family member to establish comfort and pain relief measures.

## METHOD

This qualitative research with an institutional single case-study design was undertaken at the NCP of the *Hospital de Clínicas de Porto Alegre* (HCPA) in 2009. At this public teaching hospital, comprehensive health care is offered. Moreover, the hospital participates actively in research and teaching and is considered a referral institution for PC in Brazil. The study participants were all five nurses working at the NCP and five nursing technicians, who delivered care to terminal patients and were randomly drafted, one from each work shift (morning, afternoon, night 1, night 2, night 3). The data were collected after receiving approval from the institution's Research Ethics Committee (n. 09-147) and after the participants had signed the Informed Consent Form. The research subjects participated in a semistructured interview, which was recorded and then fully transcribed and grouped per category. The interviews were held at a private room inside the NCP, during the research participants' work hours. Besides the interview, direct observation was used to register how the NCP functions, its work routine, the environmental conditions offered to the patients and their family members, as well as to the nursing professionals. All requirements established in the Brazilian guidelines for research involving human beings (National Health Council Resolution 196/96) were complied with.<sup>7</sup> To analyze the information, the thematic analysis technique was adopted, including the following phases: pre-analysis, exploitation of the material and interpretation of the results. Also, because of

the case study design, the researchers attempted to preserve the social unit as a whole, that is, besides the themes that emerged, the structural and social context of the NCP was registered in a broad sense.

## RESULTS AND DISCUSSION

The results are presented in two main themes. The first highlights some characteristics of the NCP, where the study was carried out, besides presenting its team and the initial moments of interaction with patients and family members. In the second theme, the care modes at the PC unit are focused on, highlighting the pain approach, the importance of communication and confidence, besides autonomy as a fundamental value of this care.

### A special place for people in a special situation

The creation of a unit that has been especially organized and prepared to receive terminally ill patients already indicates a logic that differs from what orders other hospital spaces, medical specialties and technological availability. The logic moves from cure to the goal of comfort and to the quality of the relations established between the team and the patient-family. This logic should be expressed in all structural and organizational configurations, and particularly in the team's preparation. Therefore, it is important to get to know the unit under study and how patients enter or are welcomed in this space.

The NCP consists of six beds, including one two-bed room and the other single rooms. Each room offers: air-conditioning, television, closet, bathroom, a board (created to allow family members and friends to leave their messages, pictures or for the patient to display poems, images or whatever he wants), an armchair with a blanket, pillow and pillowcase for the family members, which are changed once per week. At the NCP, the presence of a relative is requested 24 hours per day. A minibar is available for the family member to bring foods (s)he and the patient like, even if these are part of the patient and/or the hospital's diet.

All family members receive lunch. When the patient comes from a far-off city or is financially

unable to buy food, the nurse attempts to get all meals for the relatives.

The NCP has a living room where the family members/caregivers and patients themselves, if they are able to get out of bed, can receive visits and relax. At this room, every Wednesday, the multiprofessional team holds meetings with the patients' relatives/caregivers to share experiences and talk about their anguish. This is considered a moment of listening.

*Welcoming for the relative, where he also starts to feel he is taken care of, a part of care, in the care context because, on the other floors, he is yet another person who helps to take care of the patient, yet another one to help and turn the patient sideways, instead of another person the team needs to take care of. This is a time when we particularly take care of the caregiver (I 5).*

At the NCP, visitors are allowed until 22h; children are free to visit, provided that they are accompanied by an adult and spend short periods in the patient's room. Each relative receives a visiting card, which (s)he has to show at the gate to be allowed to the NCP. Religious services from different religions are also allowed.

*We highly respect the patient's will, his beliefs so, if they want to hold a different service from what we're accustomed to, with screams and all that, provided that they don't bring any dead or living animals, that they don't do any sacrifices, all the rest is free. That is also a form of welcoming, of humanizing care (I 5).*

Recent studies have indicated that religious or spiritual beliefs influence treatment decisions in severe and terminal situations. Spirituality expresses how people relate with a larger whole – something larger than themselves – and how they find meaning amidst their suffering.<sup>5</sup>

In PC, spirituality appears as a form of coping and is often considered as a synonym of religion, although it is of course a broader concept. The religious element can be one component of spirituality.<sup>8</sup>

Another part of the NCP is the nursing station, where the patients' files, medicines and materials are stored. The multiprofessional team includes: nurses, nursing technicians and assistants, physicians from the internal medicine team, psychologists, a social worker, among others. Each technician or assistant takes care of three patients, as all of them need plenty of attention.

The health team should include professionals from different background areas, who are able to offer holistic care to patients and their family members. These professionals need to respect differences, attempting not to judge values, be willing to inform the patients and their relatives about possibilities to face this moment in their lives, mitigating the suffering of all stakeholders, including the team itself.<sup>6</sup>

When a request comes from other hospital units to transfer the patient to the NCP, the nurse from the Center goes to meet with that patient and his/her relatives for evaluation. During this preliminary assessment, one of the requisites for hospitalization at the NCP is to verify whether the patient is lucid and orientated to be able to make the best of his/her remaining days.

*We go there, assess the patient, talk to the patient and family, and then we already start to bond. That's when we work a lot with dreams, with alternative lives, with what they believe in, with what they know about the disease, because talking about it is something few people do, and they need to hear and know that they can count on someone to talk about that (I 5).*

*During this initial welcoming, we already plan together with him, how he's going to continue being taken care of, and we already start to work on trust. We tell him that we're going to take him to another area, so we need to add value for them (I 6).*

During this interview, the family members are informed that, at the NCP, some patient interventions are not done, like calling the Intensive Care Center for reanimation for example. It is indicated that one of the goals at the NCP is symptom relief. In addition, together with the patient, ways of offering quality of life are planned, so that his/her final days do not turn into lost days.

To deliver proper care, the health team needs to have knowledge about the techniques, provide information, be considerate towards other persons, respectful, well positioned and express interest in what patients and relatives say. It is not sufficient to let the families accompany the patients. Instead, they need to be asked about their doubts, their emotions, reactions and behaviors towards the dying process need to be understood, as taking care means perceiving other people as they really are, their discourse, gestures, limitations.<sup>9</sup>

When arriving at the NCP, the patients and their family members receive explanations about the routine and the facilities are shown, as described earlier. After this information, specific care starts to relieve the signs and symptoms and control the patient's pain. In this care context, however, all professionals are caregivers. The premise is that nobody is able to take care of the patient alone.

*The physician plays the role of caregiver, as a primary caregiver no longer exists. He starts to share with us, has a previous bond, so he transmits security to the patient, and we are offering the complete structure so that everything that is planned is complied with (I 6).*

As soon as the nurses evidence the need for more specific care, they use the hospital's standard operating procedures and adapt them to the reality at that moment. In case the patients go home using a catheter and/or tracheotomy, the family members are trained to apply the necessary care.

*We already have various adapted versions. We make the technical terms more accessible. At first, the caregiver receives it in writing; then, the nurse goes there and trains several days until the caregiver is able to perform the care (I 3).*

*He leaves only when the physician has clinically discharged the patient and he is stable and, sometimes, the patients stay here two or three days longer because the relatives are not ready to leave and, when they leave, we continue monitoring them for 24 hours. They can call us to talk to the nurse and solve doubts as to what they did not understand about the diagnosis, signs and symptoms, some action related to the prescription they received. So, that avoids that they return soon, unnecessarily (I 6).*

All professionals who are active at the NCP receive training before they start working. Once per week, they meet to talk, to discuss the attitudes taken with regard to patient care and also to understand the patient as a whole.

*We had some meetings, some course before the palliative unit opened. We read a lot, received clarifications that morphine is just another drug, so some things were clarified; but there's the other side, the spiritual side, that it the human element, that's the main thing (I 1).*

*Once per week, we meet to try and understand the patient as a whole, because the patient is a whole.*

*He no longer feels pain at night because he's thinking about his death, he feels pain because this morning he saw his son or he wants to see his son. So, there's a series of things we have to understand because the pain is not treated alone, as physical, but what is bothering him at that moment, so that he and we can intervene (I 6).*

A strategy to qualify the care delivered, like in the case of team meetings, also plays the role of supporting the professionals, turning into a privileged space for continuing education. In this sense, the patients highlight the personal and group difficulties that need to be overcome by sharing both technical and affective challenges, as well as the reconfiguration of professional identities. Professionals who were trained to serve as agents of cure and predetermined therapeutic targets now need to establish new objectives and surround themselves with new tools.

*At first it was heavy. I'm not saying that it is not now but, at first, when we lost a patient, the entire team felt really bad. I think we gradually educated our organism in this respect, but you don't get accustomed to death, no, it's difficult, it's not possible. We strongly felt the loss because, at the other places where we worked, we treat the patient to get better, leave and be well, and not this patient, this patient sometimes goes home, but he's not always well, he's hardly ever well (I 2).*

*This week there was a controversy. A patient had recently received a diagnosis, and the family did not accept that there was nothing left to do. We held meetings to reconsider why certain attitudes, certain interventions were not happening, and that work was really good because we saw that, soon, we were able to make the people accept the death situation more naturally, which is not easy at all (I 3).*

Some healthcare providers – physicians, nurses, social workers, pharmacists, clergy and others – have learned to take good care, in a particular way. All healthcare providers need to know how to deliver good PC though.<sup>5</sup> According to experts, this can markedly reduce the hospitalization time.<sup>10</sup>

Specifically concerning nursing, PC education can significantly reduce the suffering and grant dignity to patients who are dying and their families. Educating not just the nurses, but the entire team, is essential to good care delivery.<sup>11</sup>

## Care modes at the Palliative Care Unit

Many patients suffer unnecessarily when they do not receive the necessary and appropriate care for the symptoms of their disease or when their anguish, suffering and needs are not understood. NCP professionals value their ability to question:

*We ask what is bothering most, the food, to know what is possible and what isn't. All routines are broken here, and that exerts a positive influence, and we assess what entails benefits and gains. But if the patient is at the NPO and wants to have an ice cream, but he is suffering from nausea and vomiting, we give medication against the nausea and vomiting and let him have his ice cream, it doesn't matter if he throws up afterwards, he had it (I 6).*

The professionals ask and the patients indicate the pain as one of the most frequent physical symptoms. Pain is considered an unpleasant sensory or emotional experience, a stressful form of suffering that causes an important reduction in the patients' quality of life when the symptom is not assessed and controlled properly. The inability to communicate one's pain is not equivalent to its absence, and the goals of PC are to completely eliminate the pain and pain symptoms when possible or to reduce them to levels the patient can tolerate in case they cannot be completely relieved.<sup>12</sup>

*The pain is a philosophy here, the pain is zero, and when they arrive in pain we have to control it within four, five, six, seven hours, let us suppose that same morning, immediately. In other words, nobody is in pain at this unit (I 6).*

*Due to the additional time they need and which I also need with them because, if I go there now and offer it, I ask if he's in pain, he might say no, but I talk to him for five minutes and I discover that he's in pain or that it's something else, perhaps not pain, perhaps just changing positions will make things better. For me, time is essential, it's fundamental (I 4).*

Pain figures among the most common and anguishing symptoms patients with advanced cancer and other terminal illnesses are confronted with. The pain-related challenge is to achieve effective relief with minimal side effects and offer this service to all patients who need these interventions.<sup>13</sup> In the United States, a study has shown that, during the final three days of life, two fifths

of all patients in all disease categories included were in strong pain.<sup>10</sup>

The nurse is expected to teach the caregiver/family member about the continuation of comfort and pain relief measures. Educative modules need to be offered about care that extends to the patient's home, as the continuous orientation process is extremely important with a view to good PC delivery at home.<sup>14</sup>

At the NCP, the nursing team discusses the care needed for catheters, tracheotomy, skin – to prevent pressure ulcers –, medicines with the caregivers/relatives. The primary notion is that the caregivers/family members participate in care and that, if the patient is discharged, they are able to deliver care more securely.

The importance of the team's educative role is evidenced. New specializations in medicine, nursing and social services based on PC have emerged to respond to the needs of severely ill patients and their relatives.<sup>15</sup>

*We elaborate hour-by-hour worksheets... with the exact times of what and how much he will receive, one table for each drug. It's for a person who does not understand anything to understand, if we need to draw, we draw it; if we need to stick the label for him to know which is which, we do it. It's different for each case. How you apply the dressing, how you change the position, at what intervals you change positions, how do you prevent ulcers on the buttocks. We address each patient with his need and with his family, with the main caregiver or caregivers. Sometimes, it takes a lot of time because you have to organize each of them, because each has a different interpretation (I 5).*

*We also prepare the relative because some emergency can happen, like a bleeding, an important dyspnea, so that he doesn't get frightened. He just has to call us and we give him the coordinates, then he comes to the emergency and from the emergency he comes back to us (I 6).*

*You have to address the same anguish, the same difficulties, the same questions [with patients and families] when the patient does not want the catheter and the family does, you have to address the family members' anxiety, the fear, to allow compliance with that patient's therapeutic planning and so that we, the team, are not the ones to boycott it (I 6).*

The PC philosophy entails the act of protecting, supporting, covering, sheltering, taking care when a certain illness can no longer be cured.

Trained PC professionals are expected to value the emotional dimension of care, developing skills that allow them to get access to that dimension and attend to each individual's specific demands.<sup>16</sup>

The trust relation between the nurse and the patient should be considered essential in nursing practice. In that sense, during their education, nurses are taught to be genuine, compassionate, free from judgment and honest, attributes that are key to trustworthiness in any relationship.<sup>17</sup>

*At this unit, the patients do not go to the ICU so, when they are going through the phase of true agony, dyspneic, we apply morphine to give them as much relief as possible, put on the Venturi mask. Since the first patient, I've lost counts of how many cases have passed by, none of the relatives have asked to go to the ICU – signaling that it is not technology they need then. It is a low-medium complexity unit, but it also has a lot of touch, being with, a lot of presence, a lot of silence too, crying when you want to [...]. Our emotions can also be demonstrated, provided that the level is under control (I 6).*

*In many case, the patient has died and, the same day as the burial, the call us at night. We see that they have a pact with us, so we are reassured because our therapeutic focus is on him and it's reaching the relative, and not just at the time of death, but also influencing tomorrow, the day after tomorrow. We even have a concept, the relatives here have defined it as Special Care, and we are defining that there is life after death for the relatives. They are already able to breathe inside their pain (I 6).*

Appropriate communication with patients and relatives is an effective measure for end-of-life care, reducing anguish, stress and anxiety by sharing the suffering with the team. In order to be a good professional, one should look at the other with great attention, pay attention to his gestures, discourse and attitudes. This guarantees that one cares about what that person is going through and feeling, and not just about the relief of his disease symptoms.<sup>18</sup>

It is also relevant to highlight that, in this care mode, self-determination represents the base to suspend therapeutic efforts for health service users. These efforts are understood as not starting a therapy or suspending it if already initiated, not resuscitating in case of a cardiorespiratory arrest,

not submitting the patient to mechanical ventilation, diet and artificial hydration against his will. Physicians and other professionals should respect the user's autonomy and let death happen at the place, time and in the company of whoever the patient wants.<sup>19</sup>

*We had a patient with an esophageal tumor, with an indication for a tracheotomy, and he didn't want to put I, the physician talked to her, said: 'look, you will die choked because your tumor is growing a lot', and she really was too dyspneic to talk, she used to talk a lot and was very dysfunctional because she was not getting enough air and she said: 'I prefer to die from a lack of air than doing a tracheotomy, and I know I'm going to die anyway, so let me die with my neck intact'. The entire family agreed because she was completely lucid and this patient ended up not dying suffocated, but she had a hemorrhage due to the tumor and we could not staunch it, she died vomiting, waving and smiling at us. It was a very strange death, but she died happily, it was a horrible death, sudden for who witnesses it, but not for her, she died with an intact neck and happy (15).*

Respect for the patient's autonomy takes into account the patient's own way of apprehending the world, of making his choices based on his own values, acting according to his principles, beliefs and worldview. Knowing how to listen is more than a quality, it's a need that favors the relation between professional and patient, reinforcing the mutual trust between them and permitting the patient's accompaniment along the decision trajectory, listening to him, clarifying his doubts and, above all, respecting him.<sup>20</sup>

In this context, accompaniment means offering company throughout a period of uncertainties and suffering when, often, the professional is unable to relieve the patient's burden, but will continue at his side until the end of the journey.<sup>16</sup> The professional's attitude of support for a patient at the exact time of death comforts him in view of shocking situations, but even professionals who follow the palliative care philosophy demonstrate weakness in their competence to face death. It is relevant to distinguish between respect for the patient's will and doing nothing to postpone his death, as opposed to the focus of professional education, which tends to be on and in favor of cure and human health.

In order to deliver efficient care to terminal patients, the team needs to move on side by side,

helping him with his decisions, without ever judging or deciding for him. According to the NCP nursing team's reports, this autonomy is well-developed in practice, so that the patient has full control over his life and treatment.

The care delivered to the patient inside the NCP goes beyond physical comfort and pain relief. This care involves touch, listening, staying silent merely holding somebody's hand, giving moral support, kindness. This care is fundamental in this final phase for patients and family members, as emphasized by different scholars.

## FINAL CONSIDERATIONS

This case study was undertaken at a Palliative Care Unit, which offers an appropriate physical and human structure to welcome patients with incurable and terminal illnesses and their relatives. This type of service is both a need and a concrete reality, which is increasingly developing, mainly with regard to the professional team and the health institutions, which have learnt how to cope with patients struck by cancer and with a limited life expectancy.

The patient's entry or transfer to an NCP represents a radical change in the therapeutic project. Therefore, it is important for this change to be desired and understood by patients and their families. The physicians who have already attended to them at other units continue on the care team and maintain the previously established relationship, thus avoiding feelings of abandonment or insecurity towards what is new. The nursing team gives attention to the patients and their relatives, which is why acts of listening, talking, supporting gain importance, even if they are expressed through silence and touch. At this unit, actions that have sometimes lost value are redefined, such as touch, being there, clarifying doubts about the medication, care, pathology, signs and symptoms the patient is showing or may show. In fact, the role of technology and the attributes of care relations are redefined, emphasizing ethical values like confidence and autonomy.

The nursing team trains all caregivers/family members for patient care. They receive training and explanations about the signs and symptoms the patient may manifest and what is the best way to take care, admitting that this "best way" is always customized and negotiated on. The

nursing team calms down the caregiver/relative, emphasizing that (s)he can contact the NCP in case of any doubt or difficulty. The family members and patients need to trust that, when they arrive at the hospital's emergency unit, the NCP will be activated to come for them, as they are now part of this new family. The team will always emphasize to the caregiver that, now, he is not just another person who takes care of the patient, but another person whose needs everyone needs to take care of, another person to be heard.

Despite the benefits these care forms produce, few specialized and well-structured places exist so far with such a well-qualified team to see to palliative care patients. At this location, inside a hospital, a possible place has been constituted to allow people to end the final phase of their life well.

At the end of the study, it was verified in practice that qualified services can be offered at a palliative care unit which, through dedication, attention and kindness, provide patients with quality of life at the end of their lives and, consequently, with a more dignified death.

## REFERENCES

- Vieira RW. Bioética, cuidados paliativos e qualidade de vida: a importância do processo de tomada de decisão [dissertação]. Porto Alegre (RS): Universidade Federal do Rio Grande do Sul, Programa de Pós-Graduação em Medicina; 2010.
- Floriani CA, Schramm FR. Cuidados paliativos: interfaces, conflitos e necessidades. *Ciênc Saúde Coletiva*. 2008 Dez; 13(2):2123-32.
- Pessini L, Bertachini L. Humanização e cuidados paliativos. 2ª ed. São Paulo (SP): Loyola; 2004.
- Alvarenga RE. Cuidados paliativos domiciliares: percepções do paciente oncológico e de seu cuidador. Porto Alegre (RS): Moria Editora Ltda; 2005.
- Last Acts National Program Office. Means to a better end: a report on dying in American today. Washington (US): Last Acts; 2002.
- Kruse MHL, Vieira RW, Ambrosini L, Niemeyer, F, Silva FP. Cuidados paliativos: uma experiência. *Rev HCPA*. 2007; 27(2):49-52.
- Ministério da Saúde (BR). Manual operacional para comitês de ética em pesquisa. Brasília (DF): MS; 2007.
- Irreland J. Palliative care: a case study and reflections on some spiritual issues. *BJNursing* [online]. 2010 [acesso 2011 Nov 30]; 19(4):237-40. Disponível em: <http://cat.inist.fr/?aModele=afficheN&cpsidt=22455307>
- Inaba LC, Silva MJP, Telles SCR. Paciente crítico e comunicação: visão de familiares sobre sua adequação pela equipe de enfermagem. *Rev Esc Enferm USP*. 2005 Dez; 39(4):423-9.
- Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AGK, et al. Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage* [online]. 2002 Feb [accessed 2012 Jan 30]; 23(2):96-106. Available: <http://download.journals.elsevierhealth.com/pdfs/journals/0885-3924/PIIS0885392401004067.pdf>
- Kelly K, Thrane S, Virani R, Malloy P, Ferrell B. Expanding palliative care nursing education in California: the ELNEC geriatric project. *Int J Palliat Med* [online]. 2011 [accessed 2012 Jan 10]; 17(4):188-94. Available: <http://ukpmc.ac.uk/abstract/MED/21537321>
- Peres MFP, Arantes ACLQ, Lessa PS, Caous CA. A importância da integração espiritual e da religiosidade no manejo da dor e dos cuidados paliativos. *Rev Psiquiatr Clín*. 2007; 34(Supl 1):82-7.
- Caraceni A, Cherny N, Fainsinger R, Kaasa S, Poulain P, Radbruch L, et al. Pain measurement tools and methods in clinical research in palliative care: recommendations of an expert working group of the European Association of Palliative Care. *J Pain Symptom Manage* [online]. 2002 [accessed 2012 Jan 30]; 23(3):239-55. Available: <http://download.journals.elsevierhealth.com/pdfs/journals/0885-3924/PIIS0885392401004092.pdf>
- Araújo LZS, Araújo CZS, Souto AKBA, Oliveira MS. Cuidador principal de paciente oncológico fora de possibilidade de cura, repercussões deste encargo. *Rev Bras Enferm* 2009 Fev; 62(1):32-7.
- Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting - a consensus report from the center to advance palliative care. *J Palliat Med* [online]. 2011 Jan [accessed 2012 Jan 08]; 14(1):17-23. Available: <http://online.liebertpub.com/doi/abs/10.1089/jpm.2010.0347>
- Araújo MMT, Silva MJP. O conhecimento de estratégias de comunicação no atendimento à dimensão emocional em cuidados paliativos. *Texto Contexto Enferm* 2012 Jan-Mar; 21(1):121-9.
- Becker AL. Ethical considerations of teaching spirituality in the academy. *Nurs Ethics* [online]. 2009 [accessed 2012 Jan 08]; 16(6):697-706. Available: <http://nej.sagepub.com/content/16/6/697.short>
- Araújo MMT, Silva MJP. A comunicação com o paciente sob cuidados paliativos: valorizando a



- alegria e o otimismo. Rev Esc Enferm USP. 2007 Dez; 41(4):668-74.
19. Ribeiro DC. Autonomia: viver a própria vida e morrer a própria morte. Cad Saúde Pública 2006 Ago; 22(8):1749-54.
20. Vicentin A, Labronici L, Lenardt MH. Autonomia do paciente idoso com câncer: o direito de saber o diagnóstico. Acta Paul Enferm. 2007 Out-Dez; 20(4):509-13.

Correspondence: Mara Ambrosina de Oliveira Vargas  
Universidade Federal de Santa Catarina  
Departamento de Enfermagem/Centro de Ciências da Saúde  
Campus Universitário  
88040-970 - Trindade, Florianópolis, SC, Brasil  
E-mail: mara@ccs.ufsc.br

Received: June 15, 2012  
Approved: December 20, 2012