Objective: to discuss the importance of applying the guiding principles of care in palliative care. Method: descriptive, bibliographic and informative study with data obtained from specialized literature over the course of 2011. Results: despite the number of services in palliative care is still small, professionals adopt their principles in an isolated manner, trying to humanize care and provide better quality of life to patients at the end of their lives. Conclusion: it is necessary to emphasize and prioritize this issue, both in the training of health and nursing professionals and in the institutions, showing their commitment to care provided to patients in all their processes of living and dying. Descriptors: Palliative care; Health personnel; Nursing; Ethics.
INTRODUCTION

Commonly, patients with diseases without prospect of a cure and at risk of death exhibit various and intense symptoms, both physical and emotional. Usually, these symptoms are mitigated by potent drugs used to control such discomforts. However, along with drug therapy, various alternatives can be used for the relief of these discomforts, such as demonstrating interest in the patients, discussing their concerns and doubts, in addition to being available to them and their families, among others. Therefore, it is necessary to overcome the view that there is nothing more to be done with a patient with no possibility of cure.

Palliative care (PC) arises as a response to misconceptions regarding the patients with no possibility of cure and at risk of death, since PC prioritizes the control of physical, psychological, spiritual, and social symptoms. The aim is to alleviate their distress, providing a dignified end-of-life process, with relief of pain and suffering. Thus, PC advocates assessing before treating, explaining the causes of symptoms, not waiting for a patient to complain, but rather adopting a therapeutic strategy, such as monitoring symptoms, reassessing regularly the therapeutic measures, taking care of the details, and being available.

The palliative treatment must be started from the moment that a disease with no possibility of cure is diagnosed leaving patients at risk of death, and not, as many believe, only at the end of life. The treatment is intended to comfort both the patients and their family caregivers, also target of this care. This way, the palliative treatment must be performed along with the curative treatment, because when a disease with no possibility of cure and the risk of death advance, the PC takes higher proportion and significance.

PC covers two important aspects, the holistic approach and an interdisciplinary professional practice, in order to benefit the patients preserving their autonomy and ability to make decisions. To that end, it is up to both the nurses and the other health professionals not to focus solely on the physical well-being of the patients, but in their integral existence. This way, they should include the bio-psycho-social-spiritual areas of the sick human beings and their families in this particular moment of their lives, in addition to help them in their daily adaptation, aiming to live with their limitations in the best possible way.

It is observed that the work of nurses, in particular, is essential for the implementation and consolidation of PC in health services, since these professionals should manage the teams and, therefore, organize, plan, and unify the members of these teams that will care for these patients in order to provide them with a more humanized care. However, despite PC has already been performed for a few decades by many health professionals, adhesion is still low in Brazil. It is observed that, particularly in the daily practice, nursing professionals use some principles of PC, even without knowing that these principles belong to PC.

From the philosophy of PC, nursing workers, specifically, can assist the patients in their dying process, having the preservation of their dignity as leitmotiv of care, since assistance goes far beyond the technique, involving ethical, ethnic, cultural, human, social, and spiritual issues. Based on these considerations and the World Health Organization (WHO), the goal of the present study is to discuss the importance of applying the guiding principles for care in PC provided to patients with no possibility of cure and at risk of death, highlighting potential difficulties faced and strategies built in the daily life of health workers, in particular nurses.

METHOD

This is a descriptive and informative study conducted through consultations of articles, textbooks and specialized texts in the course of 2011. After perusal of the material selected, the results were descriptively organized in order to achieve the goals proposed. This way, the focus was on the principles of PC in order to guide this daily work, seeking strategies to provide humanized and quality care in the dying process.

DEVELOPMENT

- Guiding principles for the practice of palliative care

The WHO, in its concept of PC formulated in 1990 and revised in 2002, provides the guiding principles for the action of the multiprofessional team in PC practices, which will be addressed below:

- Promoting relief of pain and other uncomfortable symptoms in patients

Relieving pain and other discomforts caused by underlying diseases requires a broader knowledge about analgesic medicines and the use of other non-medicinal strategies. Psychosocial and spiritual aspects should also
be addressed, since they may influence the intensity of patients’ pain.1,9,10

♦ Affirming life and considering the dying process as normal or natural

In PC, death is accepted as part of the trajectory of life, without being trivialized or rejected. The understanding of health professionals regarding the process of finitude of human beings is essential, because they may help the patients understand their diseases, accept completion of life, and live the remaining life time with quality, keeping hope and motivation.1,9,10

♦ Do not accelerate or postpone death

Among the discussions on PC, there are still professionals that consider its conception similar to euthanasia, because they believe that this philosophy means the abandonment of the patients leaving them to die. However, when using measures of quality of life, the evolution of the diseases may be delayed. The patients may begin to feel better, not only due to alleviated pain, but rather because of care provided in the physical, emotional, and spiritual dimensions.

To make this possible, it is necessary to carry out an accurate diagnosis of the disease, as well as to better understand this pathology, with the exclusion of unnecessary interventions in the care provided to those patients and procedures that extend their agony and suffering (dysthanasia), in addition to carrying out active, respectful, and embracing monitoring, creating empathic and bonding relationships.1,9-10

♦ Integrating psychosocial and spiritual aspects in the context of care

It should be noted that the process of loss starts when an incurable disease is discovered. Among others, it involves the loss of employment, purchasing power, autonomy, self-image, safety, and respect, which can cause sadness, anxiety, and depression in the patients and their families. In this sense, the interaction between the professionals of the team that will provide care to those patients becomes relevant for the optimization of the care plan for treatment. Decisions should be taken in conjunction between professionals, patients and their families. In the aspect of spirituality, issues related to the meaning of life and death are addressed, whether or not related to a religion. The main focus is the patients, with their experiences and beliefs that should be respected and managed in the best possible way, in an attempt to provide an improvement in their quality of life.1,9-10

♦ Offering a support system that allows the patients to live as actively as possible until the time of their death

This principle stresses the importance of professionals in their decision making, respecting the will of the patients and not sparing efforts in support of their better well-being, in particular during the final stage of life. The trend in most hospitals is the sedation of patients. However, PC avoids the adoption of heavy sedation schemes as much as possible, so that the patients can be autonomous and interact with the professionals and their families in order to choose the best way forward regarding treatment.1,9-10

♦ Offering a support system to assist the families during the disease of patients and bereavement

PC also provides care to the families. As well as the patients, the families should be informed about the whole situation experienced. Communication and interaction between the health team, patients, and families become invaluable and effective when used appropriately and honestly, in order to embrace and also alleviate their suffering, extending this attention and embracement during the time of bereavement.1,9-10

♦ Improving the quality of life and positively influence the course of the disease

This principle stresses the holistic approach of the professionals, in which the patients are regarded in their entirety (physical, emotional, social, environmental, and spiritual contexts), respecting their wishes and needs. The aim is to improve the course of the disease, making it less painful in the life context. As soon as the symptoms are controlled, the wishes respected, and the needs met, including the coexistence with the family members and the opportunity of fulfilling pending issues, it can be affirmed that the quality of life of these patients is being preserved.1,9-10

♦ Starting PC as early as possible along with other measures for prolonging life, such as chemotherapy and radiotherapy, including all the necessary investigations to better understand and manage the symptoms.

PC should be inserted into the patients’ treatment from the discovery of a disease without possibility of cure or potentially fatal. This care does not rule out the use of diagnoses and therapeutic resources that
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keeping an empathic and open communication. Since some professionals do not tolerate living with suffering and death, they tend to escape from this care; however, even without the possibility of cure, it is possible to follow up the patients and be supportive, which is essential at this critical time experienced by the patients.11,12

With respect to the relationship between patients and professionals, being together with the patients in discomfort and seeking ways to help them is a rewarding experience for the professionals. While devoting to PC, these professionals may be distressed by experiencing the suffering of patients; however, they will learn to evaluate what is essential in life, respecting the human condition, so fragile and finite. It may also be added the fact of being able to share skills and unique experiences with all the members of the team. One of the biggest bonuses when working with terminal patients is helping them feel more comfortable, without devices or high technologies, only using the mind, heart, and hands.13

Units in which PC is performed emphasize that care should be carried out by a multidisciplinary team. This way, it will be possible to have a larger view of the patients' situation and a better programming of the care plans. This procedure will involve physicians, nurses, nursing technicians and assistants, psychologists, physiotherapists, dieticians, and spiritual counselors, who should work together in order to provide a better quality service to these patients. It should be noted that the essence of PC is sharing dialogue and teamwork.

Even though there is not a service established in PC or actions performed by a multidisciplinary team, that philosophy can also be implemented by a nurse and a physician, with an assistant, or a family counselor, provided there is priority of this care, sharing opinions and strategies for assisting the patients.14

Currently, there is a greater awareness on the part of health professionals, especially nurses, on the need for implementation of the philosophy of PC in the care provided to terminal patients. Even though the number of CP services is scarce, it is possible to observe that many professionals adopt the principles of this philosophy in an isolated manner, humanizing the care and, at the same time, benefiting the patients with greater quality of life in their dying process.15

Among the attributions of the professionals who adhere to the philosophy of PC, the performance of nurses and other nursing
professionals is particularly present in a form of interpersonal, direct, procedural, dialogical, and subjective relationship in care provided to patients. Their actions and interactions take place both with the patients and their families, and the multidisciplinary team and the institution. Such professionals care for these patients since their admission until they leave, either due to discharge or death. Among other skills, nurses in PC should perform a careful assessment of the signs and symptoms of pain, helping the team set priorities for patients’ care, the familiar interaction with the team, and the strengthening of the guidance provided by other professionals of the multidisciplinary team.

Some elements are considered fundamental to the performance of health professionals in PC, such as “compassion”, in which the professionals seek to put themselves in the place of the patients and try to share their pain, assisting and supporting them in this critical phase of their lives, showing themselves involved and committed with care. “Humility” is also necessary in order to recognize that one cannot have the right answers for everything and is subject to continuous learning. Sharing with the team, the patients, their family members, and friends becomes enriching and rewarding. The professionals should also admit to the patients that they do not have all the answers, but they are willing to seek and bring the best answer to their questions. Another aspect is “honesty” when dealing with patients and their family members, using transparent and serene communication, explaining to them the prognosis of the disease and what can be done from that moment. Explaining to the patients the right of choice over their treatment—thus ensuring their autonomy and their dignity—is a very important precept in the philosophy of PC.

Everyday challenges and strategies in the work of health professionals, especially nurses, in palliative care

It is a fact that PC includes various types of stressors, such as organizational, professional, and emotional. By the very nature of this procedure, professionals are faced with emotional stressors, such as: repeated deaths; distress; exposure to the suffering of patients and families; difficulties of answering difficult questions to patients and their families; and personal discomfort due to suffering and death. Therefore, structures and strategies are needed to ease the burden of these professionals, reducing their stress and increasing their job satisfaction, also taking into account the improvement of the care provided to these patients.

Understanding and unity between the health team members that deal with patients with no therapeutic possibilities become paramount in order to plan the care required based on sharing of knowledge and discussions of complex subjects, which can cause anxiety and fear in the members of the team. The goal is that care is not focused only on medical assistance, but on an interdisciplinary action, involving the health team, the patients, and their family members. When the diagnosis of a disease with no therapeutic perspectives and exhibiting risk of death is made, the tendency of many professionals is to demonstrate uncertainty of how much, how, and to whom to report it. Many of them cannot reveal this condition directly to the sick person, for fear of not knowing how to deal with emotional reactions arising from this information. Generally, such news is communicated to closer family members, with the task of deciding whether to tell the truth to their sick relative and the rest of the family or keep the information telling only part of the truth.

The family member that receives a challenge as big as this one tends to suffer as much as the sick patient. From the information of a diagnosis without prospect of a cure, a physical and psychical disorganization of the family as a whole can occur, since as a unit and an organized structure this family becomes sick along with its relative. Therefore, health professionals should regard the patient and the family as a whole, supporting them to face this situation.

In PC, health professionals should be physically and psychologically prepared to guide the families in the confrontation of this suffering, since physical and emotional exhaustion may occur, with consequent psychological disorder of the family member/caregiver. Often, the relationships between the health team and family members are formal and bureaucratic, neglecting adequate attention to the family members that also require care and appreciation, because they know the patients and are much more involved with the latter than with the health team. Therefore, health professionals, in particularly the nurses, should develop some attitudes to work in PC, such as: caring for the other; being open to various discussions, including spiritual; being available to listen to the concerns, doubts and fears, respecting the wishes and the autonomy of patients and family members, learning also to
look and touch therapeutically these individuals.20

It is worth mentioning that, in addition to the cultural and spiritual factors associated with dying and death, health professionals are not sufficiently prepared to cope with feelings of defeat, loss, and death. They are oriented to cure at any cost since undergraduate studies, especially in the case of medicine and, when they run into patients without possibility of cure, they may tend to isolate them, for not having proper support for care. Therefore, introduction of knowledge about PC becomes imperative since the initial training of health professionals21 in order to understand and accept the finitude of human beings.22

In many cases, the understanding of spirituality becomes an important tool for these professionals to be able to deal with the process of death. Spirituality can be an ally, both for the professionals that will have more means to dialogue with these patients and the patients that concomitantly will benefit from the peace and tranquility coming from the possible understanding of this phase of life. Hope and strength can be increased at this moment, providing a better quality of life during the time that patients have left.23

In Brazil, it was observed that, even though PC is not recognized yet, there are some initiatives for its implementation. Health professionals direct their look deepening their knowledge in this approach and incorporating the concept of care, even if the cure is no longer possible.

Some actions are prioritized in PC, emphasizing that many of them may be closely related to the performance of nursing professionals in particular, including: hygiene and comfort; nutrition and hydration; hypodermoclysis; treatment of wounds; pharmacological techniques; palliative surgery; and palliative sedation.

Regarding "hygiene and comfort", with the advance of a disease with no prospect of cure, patients can become increasingly dependent. In most cases, they progressively require help to maintain their physical comfort and thus preserve their dignity. It is worth mentioning that these aspects should be maintained until after death. Some practices of hygiene and comfort can be mentioned, namely: environmental hygiene; aspersion bath (shower); bed bath; scalp hygiene; oral and intimate hygiene; adequacy and making of beds; diaper change; shaving; comfort massages; transference and mobilization in bed; and readjustment of clothing.24

With respect to "nutrition and hydration", the first is especially important at the beginning of the disease, when the body needs energy to fight infections and heal wounds. The patients that receive PC suffer several losses during their pathology, such as taste, swallowing, and digestion and absorption of food. Such complications tend to cause loss of confidence and self-esteem, social isolation and depression. In the final moments of life, comfort is prioritized by minimizing the stress. Therefore, if the food does not make the desired effect, feeding should be suspended, preventing further damage and suffering to those patients. However, this decision-making process leads to important religious and ethical conflicts, requiring open dialogue with the patients, the families, and the team, explaining and discussing the advantages and disadvantages of suspension or maintenance of nutrition and hydration in the patients.25

"Hypodermoclysis" consists in the administration of medications subcutaneously. It is a simple technique requiring fast handling and less time for execution. It has low cost and is prescribed to patients with collapsed and thin veins which are easily broken apart. It is worth mentioning that the most frequent use of this practice includes patients who are: unable to ingest anything orally; exhibiting full dehydration; unable to ingest analgesic medication; in need of replacement of electrolytes and administration of antibiotics; lack safe and comfortable venous access.26

Focus on "treatment of wounds" consists in measures for the prevention and control of symptoms arising from the injuries, aiming at patients' comfort.27

"Pharmacological techniques" require pharmacological treatment together with non-pharmacological measures, in order to seek relief from physical suffering caused by the progression of the disease, which produces physical pain and can lead to social and emotional suffering, in addition to limiting their daily activities.28 "Palliative surgery" is performed in PC with the aim of providing relief from pain and other symptoms, or facilitating other forms of treatment, without the goal of achieving the definitive cure.29

"Palliative sedation" comprises the administration of medicines that reduce the level of consciousness of the patient, intended to relieve symptoms arising from the underlying disease in its advanced stage. It is worth mentioning the need of authorization from the patients or family members to perform the procedure. However, before performing this intervention, the ideal would
be to solve other emotional problems such distress, anxiety, frustration, fear, lack of information, and feeling of their coming death.  

**FINAL CONSIDERATIONS**

The present study showed that PC must be performed from the beginning of a disease without possibility of cure leaving the patients at risk of death and not only as last care to be provided. To this end, it is necessary to train health professionals—in particular nursing professionals—with respect to the principles of PC, favoring their understanding and sharpening the perception of the needs of each individual, with views to the quality of palliative care.

Lack of knowledge and training of health professionals can contribute to cause greater suffering and their disengagement from sick patients without prospect of cure and at risk of death. This possible limitation confirms the need to emphasize and prioritize this issue in the process of training of health and nursing professionals as well as in health institutions, demonstrating their commitment to the care provided to patients throughout their process of living and dying. It should also be noted that there is a need to address a closer attention to the families of the patients in the process of death, offering care, support, embracement, comfort, and guidance to strengthen them in the care provided to their sick relatives. Nursing actions should be well planned in order to provide the families with a less painful experience.

This qualification, seen from an ethical, emotional, and spiritual dimension, can also reduce the experience of possible moral suffering on the part of the health team by strengthening the decision-making process regarding the care being provided in terminality situations, in addition to providing greater visibility to the nursing team and the work performed.

From the present study, it can be highlighted that it is relevant and urgent to overcome some obstacles with regard to the consolidation of such care, namely: the difficult access to palliative care services; failure of health policies guidelines; and deficiency in the training of health professionals, in addition to the lack of awareness of this subject among the general population.

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