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CONTRIBUTIONS OF THE THEORY OF THE PEACEFUL END OF LIFE TO THE NURSING CARE FOR PATIENTS UNDER PALLIATIVE CARE

Contribuições da teoria final de vida pacífico para assistência de enfermagem ao paciente em cuidados paliativos

Contribuciones de la teoría final de vida pacífica al la asistencia de cuidados paliativos

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ABSTRACT

Objective: This study investigated the contributions of the Theory of The Peaceful End of Life to nursing care for patients under palliative care. **Methods:** This field research with a qualitative approach was carried out with 12 registered nurses. The semi-structured interview technique was used for data collection. The data obtained were submitted to content analysis. **Results:** Empirical analysis allowed the emergence of two categories: "Spirituality while promoting peace during the final moments" and "Satisfying the terminal patients' desires as an attitude of respect for their dignity". **Conclusion:** As main contributions, the Theory of The Peaceful End of Life guided the strategies used by the nurses, especially those aimed at promoting peace by paying attention to the spiritual dimension and respecting the dignity of patients at the end of their lives. Furthermore, meeting their last wishes and solving pending problems were highlighted as important strategies.

Descriptors: Palliative care, Nursing care, Nursing theories, Terminal state, Death.

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RESUMO

Objetivo: Investigar as contribuições da Teoria Final de Vida Pacífico para a assistência ao paciente em Cuidados Paliativos. **Método:** pesquisa de campo com abordagem qualitativa, na qual participaram 12 enfermeiros. Para a coleta dos dados utilizou-se a técnica de entrevista semiestruturada. Os dados foram analisados mediante a técnica de análise de conteúdo. **Resultados:** da análise do material empírico, emergiram duas categorias: Espiritualidade na promoção de paz nos momentos finais; Atender aos desejos do doente terminal como atitude de respeito à sua dignidade. **Conclusão:** as principais contribuições da Teoria do Final de Vida Pacífico consistem em fornecer um suporte apropriado para nortear as estratégias utilizadas por enfermeiros, especialmente no que se refere a promoção de paz mediante a atenção a dimensão espiritual e o respeito à dignidade do paciente em fase final de vida relacionada ao atendimento aos últimos desejos do paciente e a solução de situações mal resolvidas.

Descritores: Cuidados paliativos, Assistência de enfermagem, Teorias de Enfermagem, Estado Terminal, Morte.

RESUMEN

Objetivo: Investigar contribuciones de la teoría Teoría Final de Vida Pacífica al asistencia de pacientes en cuidados paliativos. **Método:** investigación de campo con enfoque cualitativo, con participación de 12 enfermeras. Para recopilar los datos utilizados, utilice la técnica de entrevista semiestructurada. Los datos fueram analizados utilizando una técnica de análisis de contenido. **Resultados:** del análisis del material empírico, surgieron dos categorías: La espiritualidad en la promoción de paz en los momentos finales; Cumplir los deseos del paciente terminal como una actitud de respeto por su dignidad. **Conclusión:** las principales contribuciones de la Teoría Final de Vida Pacíf son proporcionar el apoyo adecuado para las enfermeras, especialmente en lo que respecta a promover la paz mediante el uso de la atención espiritual y el respeto a la dignidad del paciente en la fase final de la vida, especialmente en satisfacer los últimos deseos del paciente y resolver situaciones no resueltas.

Descriptores: Cuidados paliativos, Cuidado de enfermería, Teorías de enfermería, Enfermedad Crítica, Muerte.

INTRODUCTION

Historically, death occurred in residences with the participation of the family members. Nonetheless, it was gradually institutionalized and incorporated into the hospital environment and its technologies. This change of location affected people's perception of the process of dying as well as their posture in the face of it. To think that one day everyone will die can generate anguish and a defensive posture because people tend to not become involved in concrete death situations. This process of distancing is a form of self-protection: death might not exist to someone if he/she avoids talking about it. Moreover, this detachment is not only existential as it occurs in the daily life of families.[1]

Considering the existence of life-threatening illnesses permeated by pain, suffering and imminent death, palliative care palliative care emerges as a set of active and holistic care, for individuals of all ages, in suffering related to serious diseases and, especially, those close to the end of life. It aims to improve the quality of life of patients, their families, and their caregivers.[2]

The estimated number of people in need of palliative care at the end of their lives is 20.4 million. The highest proportion (94%) corresponds to adults, of whom 69% aged over 60 years and 25% aged from 15 to 59 years. Based on these estimates, approximately 377 adults out of 100,000 will need palliative care at the end of their lives each year worldwide.[3]

For this reason, to deliver palliative care to patients in the final stage of life, professionals should adopt therapeutic modalities to reduce suffering, pain, and other negative repercussions caused by diseases, aiming at their well-being. This modality of care also helps family members and caregivers to face the process of death and mourning.[4]

From this perspective, to meet the needs of patients with life-threatening and terminal diseases, the work of the palliative care team is of fundamental importance. Multiprofessional and interdisciplinary teams include doctors, nurses, physical therapists, dentists, social workers, psychologists, occupational therapists, pharmacists, nutritionists, religious people, among others.[5]

Care has been discussed in various fields of health, especially nursing. Viewed as a priority, care does not succumb to the need for healing and stands out through the experience of meetings, presences, calls, and responses. While caring for a patient with a life-threatening disease, negative feelings such as grief, anguish, sadness, and fear pervade an unknown world, where pain and suffering take over life in a stealthy way.[6]

Given this framework, the Theory of The Peaceful End of Life stands out as an important reference due to the similarity of its concepts and assumptions and the principles of palliative care. According to this theory, the main focus of nursing care is not on the last moment of the dying process, but rather on the contributions to a peaceful and meaningful way of living for terminal patients and other important people. It proposes the relief of real and/or perceived fears and anxieties experienced by patients and their family members. In this way, nurses can promote a more peaceful end of life for terminal patients in addition to completing the daily hospital tasks.[7]

Considering the above-mentioned, this proposal is considered relevant in the field of nursing since it may enable the production of new knowledge by applying the Theory of The Peaceful End of Life to palliative care, which is key to provide support for patients with chronic and terminal diseases.

Since little research has been conducted on this approach, the need to carry out a study to investigate the contributions of the Theory of The Peaceful End of Life to palliative care arose. Furthermore, this study was justified because it can contribute to the reflection on the ideal practices and actions to be developed by nurses delivering palliative care to patients at the end of life.

METHODS

This field research with a qualitative approach was based on the Theory of The Peaceful End of Life in light

of the Consolidated Criteria for Reporting Qualitative Research (COREQ).

The research setting was a hospital with a long-term care unit. It should be noted that this hospital provides a benchmark for palliative care in *Paraíba* State, Brazil. Employees of this health facility often care for incurable patients.

Before the main researcher started to conduct this research, it was presented to the general coordinator of the long-term care sector of the hospital. After that, the coordinator included the researcher in the work routine on the wards and introduced her to the nursing professionals.

In qualitative research, the number of participants should not be prioritized since the main focus is the understanding of a certain phenomenon. However, qualitative research must involve decisions about the selection of participants and its conditions since they directly interfere in the quality of the research.[8] Thus, the sample was not defined in quantitative terms initially, and the number of participants was determined throughout the process until no new knowledge relevant to the study was obtained from new participants.

The inclusion criteria were nurses working in the long-term care units with at least one year of professional experience. Exclusion criteria were workers on vacation or medical leave during data collection. Thus, the study sample comprised 12 nurses working in the palliative care unit.

Data collection was performed from October 2018 to February 2019. Semi-structured interviews based on the concepts of the Theory of The Peaceful End of Life were conducted. Audio recording equipment was used during the interviews, which took place in the morning and afternoon shifts and lasted an average of 20 minutes.

It is worth noting that none of the professionals invited refused to participate in the study and the choice of an appropriate environment allowed the interviews to be conducted without interruptions. The researcher responsible for data collection is a professor holding a Master's Degree and has no connection whatsoever with the study participants.

The interviews were transcribed and submitted to content analysis.[9] The methodological steps of this technique included: pre-analysis, in which the transcription of the interviews and the floating reading to determine the corpus according to the study objectives were performed; exploration of material, which consisted of codification by transforming raw data into categories, which are as follows: I. "Spirituality while promoting peace during the final moments"; II. "Satisfying the terminal patients' desires as an attitude of respect for their dignity". In the last step, which consists of the description of the results, inferences were made to elucidate what is latent in the participants' speeches and the interpretation was guided, as already exposed, by the Theory of The Peaceful End of Life.

This study complied with all the ethical norms for research involving human beings. The research started after it was approved by the Research Ethics Committee on March 20th, 2018, under Legal Opinion No. 2.553.408. In order to preserve the study participants' anonymity, they were identified with a reference code beginning with the letter N (Nurse) followed by a number representing the order in which they were interviewed (N1, N2, ...).

RESULTS AND DISCUSSION

Based on the study participants' statements, the main attitudes toward a peaceful end-of-life experience were identified.

I. Spirituality while promoting peace during the final moments

The study participants valued spirituality as a resource that helps patients under palliative care to accept their condition, providing them with peace. Spirituality, religiosity, prayers, and belief in God can tranquilize the patients during their final moments of life, as can be seen below:

> *"Through spirituality and religiosity, it's possible to feel at peace". (N1)*

> *"Peace in the final moments can be achieved through spiritual support". (N2)*

> *"I believe in the power of prayers. They bring great peace. I had a patient who didn't believe in God, but in a moment of prayer he breathed and said 'I accept Jesus' and he died in peace". (N3)*

> *"Spirituality is very important. If the person believes in God or not, it's up to the nurse to investigate whether he/she is catholic, evangelical, atheist... But even if you are an atheist you must believe in something. We have a chapel here, and there are religious shows on television... This helps to promote peace". (N6)*

> *"If we don't have a certain knowledge about the patient's spiritual dimension, his/her situation may be aggravated. We have to accompany them and help them, always giving them hope and peace. God does everything in our life". (N9)*

> *"I like to have good conversations. Talking, speaking positive words, putting God first, and respecting patients' religion. I say they're in God's care. As a result, they feel more at ease". (N11)*

II. Satisfying the terminal patients' desires as an attitude of respect for their dignity

In this category, the strategies used by nurses to preserve the dignity of patients under palliative care were revealed. Among them, the respect for the patients' last needs was highlighted:

"The dignity of the patient is maintained by respecting his/her will even if we don't understand it". (N4)

"The patients know they're going to die and their time is coming. We care for a lot of cancer patients and patients with a lot of pain. We try to satisfy their last wishes and ensure their dignity in their final days..." (N5)

"We experience excessive workload, but we can make an effort for them. We can make some of their wishes come true since they're terminal patients. We must give up our desires. We can reconcile them through conversations even if their requests are not part of the hospital's routine". (N7)

"To respect dignity is to listen to him/her and do whatever he/she wants". (N8)

"The nurse can do a lot to ensure the patient's dignity until his/her last breath. We always bring his/her family members together, interact more, solve problems, and promote forgiveness". (N10)

"We can't solve everything, but we try to respect the requests. I was asked to give a patient coffee but he couldn't take it. However, I managed to wet his mouth so that he could taste it. He passed away right after that". (N12)

In the **Category I**, the study participants reported considering "spirituality" as an important dimension for promoting peace to patients at the end of their lives. The reason is that it was understood as a necessary element for the feeling of hope, bringing meaning to life and disease, promoting tranquility, and contributing to ease the negative feelings and emotions related to the finitude process. For the study participants, prayers, and knowledge of spiritual dimension and religiosity are the main existential needs of the patients. To meet these needs, strategies such as the practice of prayer, dialogue, visits to the chapel, and the possibility of watching religious shows on television were usually employed.

Being at peace involves the feeling of calm, harmony, and satisfaction. For the authors of the Theory of The Peaceful End of Life, the experience of peace is related to a pattern in which the patient, family members, and friends maintain hope and a sense of life. They receive assistance so that practical and economic issues related to the patient's moment of death can be clarified and, above all, he/she does not die alone.[7]

Regarding palliative care, a study established the importance of spirituality within the context of serious disease. Evaluation and attention to spiritual needs were identified as important factors in promoting quality of life. Palliative care professionals are in a unique position to work as a team and explore many variables. Among them, the domain of attention to spiritual, religious, and existential aspects of care stands out. These aspects are considered as guiding principles for patients and their relatives to make difficult decisions when dealing with a life-threatening disease. Unaddressed spiritual issues can frustrate attempts to treat other symptoms and have an adverse effect on the quality of life.[10]

Among these strategies, prayers can significantly help to establish the vital signs of patients with chronic or terminal diseases or even healthy people. A study sought to stimulate the practice of prayer among healthy adults found a reduction in respiratory rates and improvement of cardiac function parameters. The practice of prayer was seen, therefore, as a health practice, which does not need to be linked to any religion and can be considered to be ecumenical.[11]

According to the study participants, religious shows were another way to promote peace through spirituality as televisions were found in every ward. A study carried out in light with the Theory of The Peaceful End of Life pointed out that many patients considered television a type of familiar distraction that ease worries and takes the focus away from the problems caused by diseases, which is an important tool for palliative care.[12]

It is worth noting that the hospital in which the study was carried out has a chapel that can be visited by patients, relatives and professionals. Visits to the chapel can give a moment of peace to patients by taking them out of the shared ward environment. As observed during the visits to the wards with more than one bed, conversations noises, routine care and crying of other suffering patients were part of daily life.

This environment can damage the feeling of peace that is directly related to calm and satisfaction and make the patients feel anxious, restless, worried, and afraid.7 The chapel was considered not only as a spiritual refuge but also one of the few places within the hospital environment where patients can stay on their own and enjoy moments of silence and meditation.

The field of spirituality in palliative care has been thriving. By comprehensively addressing the spirituality spectrum in different religious and non-religious contexts, palliative care contributes to the integrated care for patients and their relatives. Providing spiritual care depends on the approaches, measures, and interventions adopted and allows the expression of beliefs and practices.

Concerning the Category II, it was highlighted the importance of respecting their will, uniqueness, and autonomy, recognizing them as human beings who are part of a social environment and have urgent needs to be met. These needs often bear no relation to the daily routine of nursing professionals who focus on drug administration, application of dressings, and bed baths.

According to the Theory of The Peaceful End of Life, the experience of dignity and respect is associated with the act of valuing terminal patients as human beings. It is important for end-of-life patients to be included in decision-making and be treated with dignity and empathy. This concept incorporates the ethical principle of autonomy. To experience dignity and respect at the end of life, patients and family members must participate in decision-making about care.[7]

Regarding dignity, specifically involving the human finitude, the patients' self-determination to make decisions and externalize their will deserves attention. In this context, a study emphasized that forgiveness is as important as religious and spiritual beliefs because it allows individuals with potentially fatal diseases to die without guilt. While patients view these diseases as a form of divine punishment, forgiveness is a way of freeing them from this punishment and easing their suffering.[13]

Although dignity was not conceptualized, the theory affirms that people have the power to decide their own goals, in other words, they have autonomy.[9] This association is a predominant attitude among academic researchers in the field of bioethics. It is worth noting, however, that this understanding is not a consensus. Some researchers consider it possible to have dignity without having autonomy as long as the entity in question is considered to have intrinsic value.[14]

Respect for the patients' will guarantees their tranquility by fulfilling their wishes, diminishes the occurrence of ethical and moral conflicts between them and health care workers, and improve family support because their relatives do not become responsible for interfering in treatment decisions that do not correspond to their wishes.[15]

As thinking about the future can bring insecurity and anxiety, many terminally ill patients prefer to focus on the present. However, to consider that the future no longer belongs to terminally ill patients' reality is to give them another loss, which is not necessary since the future is an individual dimension and perspective regardless of any outcome. Therefore, wishes and plans are indispensable for resignifying the lives of patients receiving palliative care. People, even in a terminal situation, are alive; therefore, they have desires and goals, which must be taken into consideration while reflecting on ways to satisfy and achieve them.[16]

Nevertheless, the patients' requests were not always respected by the nursing professionals, as stated by one of the study participants:

> *"Many patients' requests aren't heard, nor met because some professionals don't understand what palliative care is. Another reason is the fact that they're dealing with personal problems, which affects their work and makes it difficult for them to care for the patients". (N3)*

The statement above emphasized that the nurse's lack of preparation for dealing with issues of human finitude, either due to the lack of training in palliative care or everyday life problems, may reflect on how they care for their patients. A study emphasized that discussions on human finitude should be stimulated among people, especially health professionals.

So, it is important to encourage respect for the preferences of the ill people and their relatives. It is vital to recognize the need to change the therapeutic approach to a quality-of-life approach and follow it while caring for patients facing life-threatening diseases and terminality.[17]

The discussion here stimulated might support further research to broaden the knowledge of strategies aimed at providing peace, comfort, dignity, pain reduction, and proximity to important people. In view of the above, the Theory of The Peaceful End of Life contributed to this study mainly by offering a promising approach for the development of scientific knowledge. Moreover, this theory allowed the improvement of the nursing practice focused on terminal patients, the expression of a unifying idea about the phenomenon, new insights on the nature of the peaceful end of life, and acquisition of deeper knowledge of nursing interventions to help patients to reach a peaceful end of life.

CONCLUSIONS

Studies on the subject are scarce, which hinders a deeper understanding of the phenomenon of terminality. On the other hand, reflecting on the contributions of the Theory of The Peaceful End of Life made it possible to identify the terminally ill patients' main needs from the perspective of nurses and relate them to clinical practice.

The analysis of the participants' statements showed that the main contributions of the Theory of The Peaceful End of Life included nursing strategies aimed at promoting peace in the final moments of life through spirituality. Meeting the patients' last wishes and solving pending problems were highlighted as strategies to ensure respect for the terminally ill patients' dignity.

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