

ORIGINAL ARTICLE

PALLIATIVE CARE AND COMMUNICATION: A REFLECTION IN THE LIGHT OF THE PEACEFUL END OF LIFE THEORY

Cristiani Garrido de Andrade¹ Isabelle Cristinne Pinto Costa² Patrícia Serpa de Souza Batista¹ Adriana Marques Pereira de Melo Alves¹ Bruna Hellen Saraiva Costa¹ Melissa Santos Nassif² Solange Fátima Geraldo da Costa¹

ABSTRACT

Objective: to analyze the contribution of nursing care, with emphasis on communication, for the patient under palliative care in the terminal phase and their families. Method: qualitative study, conducted in a Philanthropic Hospital in the city of João Pessoa-PB, Brazil, in 2019, developed with 15 family members of patients in palliative care, through semi-structured interviews. The data were submitted to content analysis, proposed by Bardin, in the light of the Pacific End of Life Theory. Results: two categories emerged: 'Communication by nursing professionals as a strategy to promote comfort, peace, dignity and respect for patients and families in palliative care'; 'The presence and dialogue of people important to the patient under palliative care are fundamental for a peaceful end of life.' Conclusion: it is hoped that, through this study, it will be possible to improve assistance to the family about communication in palliative care.

DESCRIPTORS: Palliative Care; Communication; Family; Nursing Theory; Nursing.

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INTRODUCTION

Palliative care (PC) is defined as holistic and active care to individuals of all ages that aims to improve the quality of life (QL) of patients facing problems associated with diseases that threaten the continuity of life, by preventing and alleviating the suffering of patients, their families, and caregivers⁽¹⁻³⁾. Since it is based on the idea of integral care, this care proposal covers not only the patient affected by the disease, but also his family, which is fundamental in the care unit, from the moment of diagnosis of a disease until the mourning period⁽⁴⁻⁵⁾. In this sense, care assumes an essential importance, since the family members have specific needs and present high levels of stress, mood swings, anxiety, feelings of helplessness and uncertainty about the unknown during the follow-up of the family member⁽⁶⁻⁷⁾.

Communication is fundamental to establish interpersonal relationships; besides words, it involves attentive listening, the look, and posture. Therefore, it is an efficient therapeutic tool for the promotion of integral and humanized care, and it helps in the recognition and welcoming of the biopsychosocial and spiritual needs of the patient and his family members. When this tool is used, users can participate in decisions and specific care and have a dignified treatment^(4,8-9).

Considering the importance of communication in the context of PC, it is essential to develop studies that contribute to strengthen nursing practice, supported by theories that support it. Therefore, this research uses the Theory of the Peaceful End of Life (TPEL) to analyze the communication process of the nursing team with family members of PC patients at the end-of-life phase. This is a middle range theory proposed in 1998 by Cornelia M. Ruland and Shirley M. Moore⁽¹⁰⁾. It was created with the purpose of, based on nursing interventions and expected outcomes, improving the QL of terminally ill patients and providing them with a peaceful end of life⁽¹⁰⁾. It is supported by concepts that highlight that, for a person to die with dignity, it is necessary not to be in pain; to have comfort, dignity, and respect; to be at peace, besides being close to important people who care about them⁽¹⁰⁾.

In addition, in TPEL there are six assumptions for the terminally ill patient: monitor and manage pain and make pharmacological and non-pharmacological interventions that contribute to his not feeling pain; prevent and monitor the relief of mental discomfort and facilitate rest, relaxation and contentment; prevent complications so that he is comfortable; include the patient and significant others in the decision about care, treating him with dignity, empathy and respect; being attentive to the needs he expresses, his wishes, and his preferences; providing emotional support; monitoring and meeting his medication needs; inspiring his confidence and bringing him closer to important people or caregivers; and recognizing the patient's experiences of not being in pain, feeling comfortable, being treated with dignity and respect, being at peace, and being near important people. These facts contribute to his having a peaceful end of life⁽¹⁰⁾.

Thus, this theory was chosen because its concepts and assumptions converge with the principles of PC, which suggest the relief of fears and anxiety, real and/or perceived, for the patient and his family. For this reason, this study aimed to analyze the contribution of nursing care, with emphasis on communication, for the patient under palliative care in the terminal phase and their families.

METHOD

Qualitative field research, based on TPEL. We took into consideration the criteria for reporting qualitative studies, present in the COREQ (Guideline Consolidated Criteria for

Reporting Qualitative Research) checklist⁽¹¹⁾.

The study was conducted in inpatient units of a philanthropic hospital, which presents an assistance service with a long-term care unit that is a reference in PC in the state of Paraíba, Brazil, in May 2019. Family members of hospitalized patients diagnosed with a disease with no possibility of cure under PC, admitted to the institution, participated in the research. Inclusion criteria were family members in the role of caregiver of patients diagnosed with chronic disease aged over 18 years old, in the final stage of life, according to the evaluation by means of the Palliative Performance Scale (PPS), with a score \leq 30%. Family members in the role of caregiver of patients diagnosed with chronic disease under the age of 18, and with a score higher than 40% in the PPS scale were excluded.

The PPS is a validated instrument frequently used in PC to follow the evolution curve of the disease. It provides subsidies for decision making prognosis prediction and definition of terminality⁽¹²⁾. In this survey, patients were categorized into four phases: stable (PPS between 70% - 100%), transitional (40% - 60%), end of life (10% - 30%) and death (zero) ⁽¹³⁾. The sample was intentional, using the data saturation criterion, consisting of 15 family members, with no refusals.

The empirical material was collected from February to May 2019. We chose the semi-structured interview technique, using the recording system, based on a previously prepared script with questions related to the concepts of TPEL, with the following guiding question: what communication strategies can the nursing professional use to promote comfort, peace, dignity, and respect for patients and families in PC? The interviews were conducted by the main researcher with experience in the field of palliative care, lasting approximately 30 minutes, in a reserved place in the institution itself, at alternate times (daytime and nighttime), according to the availability of the participants.

Data were analyzed using the content analysis proposed by Bardin⁽¹⁴⁾ and interpreted considering the TFVP. The analysis followed the following steps: pre-analysis, in which the transcription of the interviews and floating reading were performed to define the corpus according to the study objectives; material exploration, which consisted of coding and decomposing the corpus of the empirical material. In the last stage, treatment of the results, inferences were made to elucidate what was latent in the participants' speeches. The interpretation was guided by the TPEL. To identify the participants and preserve their anonymity, the initial F was used as a code, followed by Arabic numerals corresponding to the order of the questionnaires in the Excel 2010 spreadsheet (F1, F2...F15).

The study was approved by the Research Ethics Committee, under opinion number 3.102.808. All national and international recommendations for research with human beings were followed.

RESULTS

Of the 15 family members participating in the study, 11 were female, and four were male. Two were between 20 and 29 years old; five were between 30 and 39 years old; three were between 40 and 49 years old; and five were between 50 and 60 years old. As to schooling, seven had completed high school; three, elementary school; four, high school; and one has a college degree. Regarding religious affiliation, nine professed the Catholic religion, four were Protestant, and two had no religion.

The categorization process was developed from the representation of the participants' reports, anchored in a reflective process considering the TPEL. With the referential, it was possible to build two categories: I. The communication of nursing professionals as a strategy to promote comfort, peace, dignity and respect for patients and families in PC; and II. The presence and dialogue of people important to the PC patient are fundamental

for a peaceful end of life.

Category 1 - Communication by nursing professionals as a strategy to promote comfort, peace, dignity and respect for patients and families on PC

In this category, the family members' statements highlight the importance of communication to establish bonds and provide comfort, peace, attention, love, joy, affection, dignity, and respect, as these excerpts show:

Communication is important and necessary, because even if the patient is not conscious, he will feel more secure and comfortable when he communicates, and so will the one who is accompanying him [...]. If the professional takes care and talks with love and affection everything flows calmly, with peace and comfort. (F1)

When the professionals arrive, talking to my mother, playing with her, with joy, my mother is happy and at peace, and then I am happy too. [...] Yes, the nursing professionals respect us, because although there are many people here, we go, communicate with them, sometimes it takes a while, but they come to assist us (F2)

The conversation improves his comfort and peace [...]. When professionals talk to him, I feel that he is being respected, that his rights are being attended to (F3)

They talk to us and respect us. Usually they go there, give medicine when we call them. [...] always when they do something that she doesn't want, they respect her will. (F5)

[The attention and the dialog are very important to bring peace to us. They make it very clear what is going on, it has happened that someone comes with the word, and he is calmer. Here they do what they can to improve comfort. (F6)

The professionals have that care and communicate with us, listen to you, attend, treat with affection, with love. [...] (F7)

Category 2 - The presence and dialogue of people important to the PC patient are fundamental for a peaceful end of life

This category highlights the importance of dialogue and closeness of the family with the patient at the end of life, considering the moment in which they are. In the view of family members, the presence of close friends is essential for a peaceful end of life and the distance from them is signaled by the perception of abandonment, sadness, anxiety, and anguish in patients at PC. The following excerpts confirm this assertion:

Granddaughters and daughters, whenever she needs us, we are all together, talking about her and with her, every day someone comes here. Always one or the other or all of them. (F8)

She always asks for her children and her husband a little, but not all of them are present. This phase is very difficult, I end up staying with her more and I feel that she feels sad and abandoned, she cries a lot. (F10)

My aunt always asks about her children, but they live far away, they don't pay enough attention to her. She cries, she feels very abandoned by her husband and family. She asks a lot about them. (F12)

For her the most important thing is her children, and they always try to take turns. The boys don't come as much. Although I stay more time with her because I am her niece, she feels very happy when they are present, talking to her, some of them try to come here. (F13)

She asks about the children, for them they are the most important in this life, but I think the

children are a little inattentive, my sister misses her family a lot, she feels sad. (F15)

DISCUSSION

Communication is a relevant tool that aims at stimulating patients and their families to verbalize their anxieties, concerns, and doubts. Thus, a bond is created, which solidifies the basis for interpersonal relationships and brings tranquility and trust, aiming at providing well-being and alleviating suffering^(9,15).

Regarding Category 1, most of the statements mentioned that it is very important for nursing professionals to dialogue with patients and their families, giving them attention, love, listening, affection, and joy, therefore, providing them with comfort and peace. They also mentioned that it is fundamental that these professionals understand that dignity and respect are a right of these patients.

Authors assert that communication - verbal and non-verbal - between the patient, his family and the professional is an essential component of end-of-life care, because it makes it possible to identify his real needs with agility and understanding. This is a way to provide special therapeutic assistance, promoting comfort and peace, which are necessary in this phase to integrate and humanize care⁽⁹⁾. This was evidenced in the testimonies of family members, in which it was clear that professionals use communication to provide comfort and/or peace to patients and their families, which corroborates the concepts of TPEL⁽¹⁰⁾.

According to this theory, comfort provides well-being to the patient and involves everything that makes life easy or pleasant, while being at peace means having more tranquility, from the physical, psychological, and spiritual point of view, and involves the feeling of serenity, calm, harmony, satisfaction, and contentment. Thus, the actions of nursing professionals should be aimed at reducing anxiety, worries, restlessness, and fear⁽¹⁰⁾. Peace and comfort must be offered in an individualized manner, to provide a pleasant and welcoming environment that generates physical, spiritual, and psychological well-being, also stimulating the presence of family members with the patient⁽¹⁶⁾.

Still in relation to communication, the importance of the non-verbal component is observed, since the study participants reported that the care, attention, and love provided by professionals are essential in the context of PC. A study indicates that they convey safety and relief to the patient, since their feelings - mistrust and afflictions - become better understood, and this helps them in the final stage of life⁽¹⁷⁾. The TPEL converges with this type of strategy and improves the nursing care provided to family members and patients in this context, because they are often not able to communicate their pain, anguish, and sadness^(10,18).

The optimistic and good-humored focus on communication between nursing professionals and patients and their families, who experience the finitude of life, was emphasized in the statements. Authors state that good humor among patients, family members and the nursing staff build therapeutic relationships that relieve the tension caused by the severity of the condition⁽¹⁹⁾.

Other aspects emphasized in the participants' speeches were dignity and respect that, in the view of family members, result from the effective communication of nursing professionals with the family and patients. According to the TPEL, dignity and respect portray this patient as a unique being, part of a social environment, whose events and feelings of experience are personal and individual, which is why one should consider their wishes and include them in the decision making, without discarding their right to defend themselves, even if they are dependent. Therefore, he should not be exposed to any situation that violates his integrity and values⁽¹⁰⁾. The respect for the patient's will deals with the right to exercise his autonomy, exposing his wishes regarding the treatments he would like, or not, to undergo if he is capable of expressing his wishes, guaranteeing, besides the relief to the patient by the fulfillment of his wishes, the reduction of ethical and moral conflicts between him and the professionals, and the support to the family members, who are relieved of the need to intervene in decisions about the treatment⁽²⁰⁾.

From this perspective, it is very important to know the bioethical principles that guide more assertive actions and minimize suffering. This is a way to bring the team closer to family members and patients and contributes to humanization in health care⁽²¹⁾.

A study shows that respect for the autonomy and individuality of patients and their families is consistent with the bioethical principles that concern the attitude of nurses towards the family, starting from the admission of patients to the PC unit, when nurses provide daily information about the care provided and participate in the communication process, using this link to improve care⁽²²⁾.

This means that nursing professionals should recognize that verbal and non-verbal communication are effective components to promote comfort and peace for the end-of-life patient and his/her family members, as an essential part of treatment. In this sense, it is important to use an appropriate language, passing on information that comforts, clarifies, and dignifies human finitude.

Category 2 reveals that family presence and dialogue are essential for a peaceful end of life. According to the TPEL, having proximity to loved ones generates a feeling of connectivity with other human beings. This theory considers the family system as a space that provides the best state of harmony and calm, with the proximity of family and loved ones to give you the proper attention. This is justified because terminally ill patients need to be closer to their families, friends, and/or caregivers to strengthen bonds and reciprocity⁽¹⁰⁾.

These bonds were elucidated in the statements of the participants, who reported that they are greater with the children, who are also the ones most responsible for the care, according to the results of this research. From the moment that the family recognizes itself as the center of the offer of care and takes full responsibility for this task, a positive command process begins in the coping strategy that the patient employs, in decision making, in daily self-care tasks and in the expression of affection. Therefore, caring for a family member at the end of life, manifesting solicitude, makes the caregiver enter the existential dimension of the other and build his/her health and well-being⁽²³⁾.

According to the assumptions of the TPEL, patients and their relatives should receive nursing care with an approach that focuses on guiding people who are close to them; promoting the physical presence and participation of relatives, so that they can participate in the care, if necessary; mitigating the negative feelings of the patient and the people close to them, such as worries and doubts; and promoting opportunities for family intimacy⁽¹⁰⁾.

For nursing professionals, the valorization of care is essential because, without the support and information from the team, with the family distance, living with the disease and its limitations can be an abstract experience that not always contemplates all the health and personal needs of the individual. Therefore, it is necessary to guide patients and their families, so that the termination of life may be smoother, through active listening, open dialogue, and humanized attitudes, supporting these people and providing them with emotional comfort in facing the transformations that occur in this phase^(6,24).

In some statements, it was clear that the distance from family members generates in patients a feeling of abandonment, anxiety, anguish, sadness and crying. These findings were also verified in another study, when negative emotions provoked by the final phase of life were demonstrated, emphasizing that they can be the result of the distance between the patients' families⁽²⁵⁾.

In the context of PC, the presence of the family and their dialogue with the patient at the end of life contribute to a peaceful end of life, as recommended by the assumptions of the TPEL⁽²⁴⁾. In view of the above, it is possible to identify in the statements of the family members of patients in the final stage of life negative feelings due to the distance from the family. Thus, it can be considered that the presence of the family with the patient is primordial for a peaceful end of life.

It is considered that the lack of studies on this theme may be a limitation for the data generated to be compared in greater depth. This means that new studies are essential in this area, in order to elucidate the possible needs of PC patients and unveil communication strategies that can raise nursing care to a new level of care and socialize knowledge on the subject based on the TPEL.

CONCLUSION

The patient at the end of life needs to be cared for until the last moments, with dignity and a good QL. Therefore, this study contributes to the construction of knowledge about communication as a strategy when it comes to caring for this group of people, and the importance of the presence and dialogue of people important to the patient and family in PC.

According to the results presented, it was evident that nursing care is based on verbal and non-verbal communication, essential components to provide comfort and peace to end-of-life patients and their families, in addition to the professional's commitment to guarantee them dignity and respect. The data pointed out that the fact that the families of these patients are dialoguing with them contributes for them to have a peaceful end of life, because detachment causes negative feelings. To prevent this from happening, the nursing team must strengthen the bonds with the family members and help that aims to give them emotional support and comfort, and consequently reduce the anxiety and suffering of those involved in this phase, providing a peaceful end of life for the patient.

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Corresponding author: Cristiani Garrido de Andrade Universidade Federal da Paraíba – João Pessoa, PB, Brasil E-mail: cristiani_garrido@hotmail.com

Role of Authors:

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - Andrade CG de, Costa ICP, Batista PS de S, Alves AMP de M, Costa BHS, Nassif MS, Costa SFG da; Drafting the work or revising it critically for important intellectual content - Andrade CG de, Costa ICP, Batista PS de S, Alves AMP de M, Costa BHS, Nassif MS, Costa SFG da. All authors approved the final version of the text.

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