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## Cuidados paliativos e comunicação: estudo com profissionais de saúde do serviço de atenção domiciliar

Palliative care and communication: study with health professionals of the home care service

Cuidados paliativos y comunicación: estudio con profesionales de salud del servicio de atención domiciliar

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### ABSTRACT

**Objective:** To investigate whether professionals of the Home Care Service value communication in the scope of palliative care, when assisting patients without possibility of healing, and to ascertain the facilitating communication strategies used by these professionals for promoting palliative care. **Methods:** This is an exploratory research, with qualitative nature, conducted with 22 professionals of the Home Care Service situated in the city of João Pessoa/PB. Data were analyzed by means of the content analysis technique. **Results:** The analysis gave rise to two categories: “Valorization of communication in the relationship between health professionals and patients under palliative care” and “Communication strategies used by professionals for promoting palliative care in the Home Care Service”. **Conclusion:** It can be concluded that communication is configured as an essential component of patient care and is extremely important for promoting palliative care.

**Descriptors:** Palliative care, Communication, Household.

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## RESUMO

**Objetivo:** Investigar se profissionais do Serviço de Atenção Domiciliar valorizam a comunicação, no âmbito dos cuidados paliativos, ao assistir o paciente sem possibilidades de cura, e averiguar quais são as estratégias comunicacionais facilitadoras que estes profissionais utilizam para promoção dos cuidados paliativos. **Métodos:** Pesquisa exploratória, de natureza qualitativa, realizada com 22 profissionais do Serviço de Atenção Domiciliar localizado na cidade de João Pessoa/PB. Os dados foram analisados por meio da técnica de análise de conteúdo. **Resultados:** Da análise, emergiram duas categorias: “Valorização da comunicação na relação entre os profissionais de saúde e o paciente sob cuidados paliativos” e “Estratégias comunicacionais utilizadas para promoção de cuidados paliativos pelos profissionais do Serviço de Atenção Domiciliar”.

**Conclusão:** Conclui-se que a comunicação configura-se como um componente fundamental do cuidado com o paciente e é de suma relevância para a promoção dos cuidados paliativos.

**Descritores:** Cuidados paliativos, Comunicação, Domicílio.

## RESUMEN

**Objetivo:** Investigar si los profesionales del Servicio de Atención Domiciliar valoran la comunicación, en el ámbito de los cuidados paliativos, al asistir al paciente sin posibilidades de cura, y averiguar cuáles son las estrategias comunicacionales facilitadoras que estos profesionales utilizan para promoción de los cuidados paliativos. **Métodos:** Investigación exploratoria, de naturaleza cualitativa, efectuada con 22 profesionales del Servicio de Atención Domiciliar localizado en la ciudad de João Pessoa-PB. Los datos fueron analizados por medio de la técnica de análisis de contenido. **Resultados:** Del análisis, surgieron dos categorías: “Valoración de la comunicación en la relación entre los profesionales de salud y el paciente bajo cuidados paliativos” y “Estrategias comunicacionales utilizadas para promoción de cuidados paliativos por los profesionales del Servicio de Atención Domiciliar”. **Conclusión:** Se concluye que la comunicación se configura como un componente fundamental del cuidado con el paciente y es de suma relevancia para la promoción de los cuidados paliativos.

**Descriptor:** Cuidados paliativos, Comunicación, Domicilio.

## INTRODUCTION

Scientific and technological development in the health field, seen in recent decades, has promoted considerable increase in the field of diagnosis and treatment, contributing, in an undeniable way, to increase the survival of patients, which makes the cases of natural death increasingly rare. However, it has been developed an approach more focused on healing than in patient care and welfare. In this context, palliative care emerges.

Since 1990, the World Health Organization (WHO)<sup>1</sup> adopted the philosophy of palliative care as a humanized therapeutic care of patients whose disease does not respond to curative treatment, especially when the disease is in advanced and progressive phase.<sup>2</sup> It is a therapeutic approach that involves appropriately trained multidisciplinary team, in order to identify and reduce problems in the physical, psychological, spiritual and/or social spheres.<sup>3</sup>

In this sense, this modality is oriented towards the relief of suffering, focusing on the sick person and not in the person's illness, recovering and revaluing interpersonal relationships in the dying process, using as key methods the compassion, empathy, humility and honesty,<sup>4</sup> adding quality of life to the days left to the patient and their families through a variety of care strategies, among which communication stands out.

Communication can be perceived as a method of exchange and understanding of sent and received messages, through which people perceive themselves and share the meaning of ideas, thoughts and purposes.<sup>5</sup> So, it goes far beyond words and content, as it comprises attentive listening, the look and the posture. Thus, communication - one of the basic modalities of palliative care - is essential so that one can receive care based on humanization, as the proper use of this feature is a therapeutic measure of paramount importance for patients in need of care, especially for those in terminal stage.<sup>6</sup>

It is noteworthy, therefore, that such type of care is still being built and, therefore, its action strategies consist of real challenge for the health teams, predicting the action of an interdisciplinary team, in which each professional, knowing the limit of their work, will contribute so that patients have dignity in their death. Consequently, such care should not be restricted to a mechanical action, to perform procedures; the person who really takes care of the being who is cared for.<sup>7</sup> must compose it in a way that spread interest, concern, responsibility and interaction

It should be noted that palliative care can be carried out in different contexts, such as in general health institutions where the patient is hospitalized, in a specific unit within the health institution dedicated exclusively for this purpose, in social institutions that receive patients with cancer for performing antineoplastic treatment, and also at home.<sup>8</sup> In this context, we highlight the Home Care Service (SAD, in Portuguese).

The ordinance nº 963/2013 redefines Home Care under the Unified Health System (SUS), describing the SAD as a substitutive or complementary service to hospitalization or outpatient care, responsible for the management and operation of Home Care Multidisciplinary Teams (EMAD, in Portuguese) and Support Multidisciplinary Teams (EMAP, in Portuguese), valuing new spaces and new forms of organization of technologies, such as palliative care. Therefore, the SAD is composed of nurse, psychologist, doctor, social worker, pharmacist, nutritionist, dentist, occupational therapist, physical therapist and speech therapist.<sup>9</sup>

It is worth noting that household care practices are intertwined by various feelings such as guilt, fear, affection, gratitude, conflicts, retribution, love and even changes in the physical and emotional state of those involved in the care. Besides, they also bring the need to reframe the relationship and develop new strategies for dealing with the proximity of the end, when the caregiver is chosen by obligation.<sup>10</sup>

However, despite the relevance of this issue, there are few publications about palliative care in home care in the national literature. Hence, our interest in conducting further studies

that can disseminate knowledge about the importance of care at home, directed to patients without possibility of cure.

Based on this understanding, the proposed study has the following guiding questions: how SAD professionals value the communication in the context of palliative care, when assisting patients without possibility of cure? What are the enabling communication strategies that these professionals use to promote palliative care?

Given the above, this study aimed to investigate whether the SAD professionals value the communication in the context of palliative care, when assisting patients without possibility of cure and investigate the enabling communication strategies that these professionals use to promote palliative care.

## METHODS

This is an exploratory research with qualitative approach and its main purpose is to develop, clarify and modify concepts and ideas, in order to get a general understanding of a particular fact.<sup>11</sup>

The scenario of the research was the SAD from the city of João Pessoa, Paraíba. For sample selection the following criteria were adopted: being working during the data collection period; having at least six months of work in the selected institution for the proposed research; and having availability and interest in participating in the study. Therefore, the sample consisted of 22 professionals, of whom 2 are psychologists, 3 nurses, 4 physical therapists, 3 nutritionists, 5 speech therapists, 4 doctors and 1 nursing technicians.

Data were collected from April to May 2015, through a form containing relevant questions to the proposed research objectives, such as: for you, what is the importance of communication in care directed to patients without possibility of cure and their families? What are the communication strategies used by you to facilitate interaction with those who experience the final stage of life?

In the analysis, authors used the interview technique, held from Monday to Friday, at times previously scheduled with the institutions and the study participants. It is noteworthy that, after the interview, the reports were transcribed in full, a procedure aimed at ensuring the reliability of data collection.

The empirical material arising from the interviews was coded in order to maintain participants' anonymity. Thus, professionals' testimonies were grouped by area of expertise and referenced by acronyms: Psych. (Psychologist), Nr. (Nurse), PT. (Physical therapist), Nt. (Nutritionist), ST. (Speech therapists), Dr. (Doctor) and NT. (Nursing technician), followed by the corresponding numbers.

The material was qualitatively analyzed through content analysis according to Bardin,<sup>12</sup> which consists of a set of techniques that are designed to obtain systematic and objective procedures to describe the content and the indicators of the messages, which make possible to organize these messages according to categories of communication.

The conduction of content analysis had three stages: *pre-analysis*, *material exploration* and *treatment of results*.

It should be noted that the study was conducted considering the ethical principles contemplated by resolution no. 466/2012 of the National Health Council, and the research was approved by the Ethics Committee of the Faculty of Medical Sciences of Paraíba (FCMPB) under the Certificate of Presentation for Ethical Consideration nº 43737215.9.0000.5178.

## RESULTS AND DISCUSSION

The study presented valuation and communication strategies as a form of palliative care for SAD professionals. Study participants' speeches allowed the emergence of the following categories: Valorization of communication in the relationship between health professionals and Patients under palliative care; and Communication strategies used by professionals for Promoting palliative care in the Home Care Service.

### Category I – Valorization of communication in the relationship between health professionals and patients under palliative care

Communication is a key factor for the health care, especially toward the patient without possibility of cure. Therefore, it is essential that health professionals establish a positive interpersonal relationship with the patient to understand their experiences and, thus, the assistance will be developed in all its fullness, based on palliative care.

In this relationship, professionals seek to provide comprehensive care to patients. Therefore, the communication as a form of palliative care is presented as one of the most important tools to promote a humanized care to the patient without possibility of cure, as evidenced by the excerpts of the testimonies, as follows:

*“Communication is always very important in any circumstance of life, especially when the patient does not have possibility of cure. Through it, we can give a word of comfort, answer questions and interact better with all who are somehow involved.” (NT. 01)*

*“Communication is extremely important for social interaction and quality of life.” (ST. 01)*

*“[...] usually, both the patient and the family are very fragile. This communication is a means of expression of pain and limitation as a caregiver, shows us the center of the fragility and directs our care properly, as a professional and person.” (Dr. 01)*

*“I use communication to make them understand that they are not alone and to strengthen them spiritually to face with dignity the final moment.” (Dr. 02)*

*“Communication plays a key role in the transfer of information related to necessary care to the patient and also in the acceptance of the disease and its consequences.” (Nr. 01)*

*“Communication must exist to raise patients’ self-esteem, because most of them are depressed [...] It improves the relationship between the professional and the patient and may also contribute through warm words, knowing the proper time to say them.” (ST. 02)*

The excerpts of the interviews show the importance of communication with patients without therapeutic possibilities in the context of palliative care, with a view to better interpersonal relationships, meeting specific needs and improving the quality of care at home.

Authors have reported that communication is essential to establish a good interpersonal relationship between the caregiver and the being who is cared for, providing an ideal environment for the expression of values, meanings, fears and anxieties<sup>13</sup>. Therefore, communication is the basis for the practice of palliative care and may reduce health problems caused by the advanced stage of the disease,<sup>6,13</sup> as evidenced by the following statement: “[...] communication is very important, because through it one can advance in treatment, reduce symptoms and provide significant improvement” (Nt. 1).

A retrospective cohort study, conducted in Italy with 402 patients demonstrated the effectiveness of palliative care and communication at home for patients in terminal stage. It was seen that when such practices are carried out effectively and through an interdisciplinary team, this benefits the patient and their families, reduces the likelihood of patients treated at home be hospitalized, and allows them spending the final period of their lives in the home environment.<sup>14</sup> In turn, researchers have stated that the effectiveness of palliative care at home depends on regular monitoring and stability of health programs, since these are the responsible for monitoring patients and professionals responsible for home visits.<sup>15</sup>

It is also noteworthy that this practice constitutes an effective tool in identifying care needs, in creating bond and in trust relationships with patients under palliative care and their families, so that care reach significant dimensions through exchange and sharing of emotions and feelings.<sup>13</sup> These facts were demonstrated in the following reports: “It is important to strengthen the bond, the trust relationship between caregiver, patient and family [...]” (PT. 01); “Communication is a key point for creating bond with the patient, to provide clarification, guidance and continuity of care [...]” (PT. 02).

It is noteworthy, then, that proper communication almost always promotes interpreting effective information and minimizing anxiety and distress of those who are near death, promoting higher quality care and achieving higher personal satisfaction.<sup>13</sup> Therefore, communication appears as an effective method of care to patients under palliative care in the home environment, and is of fundamental importance for the promotion of human assistance.

## **Category II – Communication strategies used by professionals for promoting palliative care in the Home Care Service**

Category 2 highlights the communication strategies used in care to patients under palliative care in the SAD field, and whose proper use is very important and hence allows a holistic, quality and humanized care.

It is noteworthy that interpersonal communication in health and in palliative care is a complex process that involves perception, understanding and transmission of messages in the interaction between patients and health professionals, and may occur verbally and non-verbally, as the following lines highlight:

*“For those who cannot talk, I not use verbal and nonverbal communication, as though they did not have speech, they still communicate in another way, that is through the look or touch, and, in addition, words of comfort.” (ST. 03)*

*“I think in this situation the presence, the look and the touch become much more important than verbal communication effectively.” (Nr. 02)*

*“I believe that in a terminally ill situation, listening and commitment to understand patients’ needs is relevant, taking into account also the nonverbal communication, their expressions.” (Nt. 02)*

*“[...] When possible, establishing an active, spoken communication, or often-through touch, look and gestures.” (PT. 03)*

*“Simple and easy verbal accesses communication.” (ST. 04)*

*“Verbal communication, always loving, caring touch and look.” (Nr. 03)*

Thus, it is clear that communication is a process that has two dimensions: verbal and nonverbal. Verbal communication takes place through the expression of spoken or written words. Through it, health professionals can use various techniques to establish a positive interpersonal relationship with the patient without possibility of cure, such

as: promoting empathy and an interaction environment; repeating the information as needed; making sure that communication was understood; listening; using appropriate tone of voice, being honest and transparent; having available time and making themselves available; maintaining a consistent speech and using colloquial language. Non-verbal communication is featured by mode and tone of voice with which words are spoken; gestures accompanying the speech; looks and facial expressions; physical contact, touch, body posture; and active listening.<sup>4</sup> These facts were highlighted in the aforementioned speeches, which showed that professionals use different forms of communication in care to patients without possibility of cure.

It is worth emphasizing that the use of strategies for a good communication within the home palliative care is of paramount importance to know the biopsychosocial and spiritual needs of patients and their families, seeking a positive interaction between the participants in the process and a greater participation in decision-making. The following statements evidence different communication strategies described by SAD professionals.

*“Listening/dialogue, to feel the level of understanding of each person on the meaning of life, quality of life, spirituality and death.” (Dr. 03)*

*“A key strategy is to target the religion, regardless of which it is, and also talking about overcoming.” (PT. 04)*

*“I use the music therapy with joy to facilitate interaction and sometimes prayer.” (ST. 05)*

*“Music therapy, qualified listening and group dynamic activities.” (Psych. 01)*

*“[...] family dynamics, modified writing, listening, interaction with the patient and music therapy.” (Psych. 02)*

*“Affective touch, attentive listening, look, storytelling that enhance self-esteem and music with playful songs that encourage laughter.” (Dr. 04)*

*“It is important to use an interdisciplinary approach, observing the clinical and psychosocial needs of patients and their families with counseling and support.” (Nt. 03)*

Such statements highlight some verbal and non-verbal communication strategies, such as family dynamics and group dynamics, music therapy, affective touch, writing, attentive listening, look and storytelling with a view to social interaction between the professional and the patient. It is worth noting that religion and spirituality, mentioned

by some participants, are palliative care strategies, not communication strategies, as evidenced in parts of the deponents. Authors have reported that such palliative care strategies need verbal and non-verbal communication to support the professional practice in this area.<sup>16</sup>

A multicentric and field research held in four health institutions and in a higher education institution located in the city of São Paulo, which aimed to discover whether health professionals know interpersonal communication strategies or techniques that enable interaction with patients in palliative care, found little knowledge of communication strategies for interaction with patients in palliative care: the majority of subjects (57.7%) was not able to name at least one appropriate strategy of verbal communication and only 15.2% highlighted the non-verbal strategies requested. These facts go against the present study, given that some professionals reported having an understanding, although limited, of communication strategies.<sup>4</sup>

As for music therapy, this was reported by four study participants as a communication strategy. It must be pointed out that music is a complementary therapy for conventional treatments. It is part of the communication process and helps in the recovery of patients with no chance of cure, given that it allows them to forget distress and the experienced and shared suffering.<sup>17-18</sup>

In research conducted on the use of music in the home palliative care, it was found that the exposition to musical encounters in terminal stage of life of people with cancer enlivens pleasant feelings that contribute for their well-being and for their families', giving meaning to their days; it also promotes feelings of joy, making them more communicative, as if the disease stopped in that time and space; it is a psychosocio-spiritual support that awakens strength and courage to transcend the anguish of their experience.<sup>19</sup>

Study participants also highlighted active listening: *“I use [...] attentive listening to improve patients' self-esteem” (Nr. 3)*. It is noteworthy that listening is an active and complex emotional and cognitive process, that emerges from auditory perception and considers the variables: attention, interest and motivation. It demands attention to hear with the desire to understand the other, considering that there is a greater expressive context behind the words spoken.<sup>20</sup>

Another strategy mentioned by psychology professionals of this research was the group and family dynamics. It is important to mention that the national and international literature is scarce about family and group dynamics as communicative strategy for palliative care essentially in the home environment.

Regarding touch, gesture, look and writing, a research showed that understanding and perception of feelings, distrust and distress, as well as the understanding of the importance of touch, gestures, expressions, looks and symbolic language are essential for the patient and the family who experiences the finiteness of life. Such non-verbal

communication strategies, when used properly, provide patient safety and patient comfort.<sup>6-21</sup>

Therefore, participation in the care in verbal and non-verbal ways with the use of strategies depends on the openness established between the professionals and the patients involved, in order to allow their proximity in the existential relationship.<sup>22</sup>

Thus, there is need of training for professionals about palliative care with emphasis on communicative skills, as highlights the speech: *“we do not have training to develop communication with the patient who does not have cure; it is very difficult”* (Nr. 4). Japanese researchers conducted an interventional study, which aimed to develop palliative care training for professionals, and reported that after an intervention program in palliative care, there was enhancement of communication by health professionals working in the home environment, cooperation between regional health professionals and they declared a variety of ways of how communication and cooperation influenced the daily practice.<sup>23</sup>

Therefore, it is believed that only through education of professionals it will be possible to train not only professionals expert in palliative care, but those who, in face of a patient with advanced disease, are able to develop strategies to provide care effectively, essentially communication, and therefore provide care that offers comfort and tranquility to the patient and their families, contributing to the improvement of care quality.<sup>24</sup>

## CONCLUSIONS

These professionals' reports emphasize communication as an essential method of care for the patient at home. The communication process is an effective element to care for patients without possibility of cure and is of paramount importance for the promotion of palliative care.

It was evident that professionals consider communication as an indispensable tool to care for patients without possibility of cure, since, through it, one can solve doubts, minimize anxiety and distress, promote comfort and thus improve the quality of care provided.

As for the communication strategies described by SAD nurses in patient care, it was found that the study participants understand, even if in a limited way, both verbal communication and non-verbal communication and use words, gestures, touch, music and attitudes for this purpose. These modes of communication are essential to provide a humanized and quality care.

Based on this understanding, it is expected that this research will enable new thinking in regard to the use of communication in palliative care at home in order to alleviate the suffering of patients and families involved in this process. Therefore, considering such research results, as well as the incipient quantitative research that address the communication process with patients without healing prognosis, although it is well structured in other health

practices, future studies in the area are needed to define the exact role of communication in care to patients in palliative care at home. Advances must derive from the further development of clinical and scientific research and from the use of communication in the professional practice in palliative care.

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