



COMMUNICATION AS AN EXPRESSION OF HUMANIZED END-OF-LIFE CARE: A SYSTEMATIC REVIEW

A COMUNICAÇÃO COMO EXPRESSÃO DO CUIDADO HUMANIZADO EM FIM DE VIDA: REVISÃO SISTEMÁTICA

COMUNICACIÓN COMO EXPRESIÓN DE LA ATENCIÓN HUMANIZADA EN EL FINAL DE LA VIDA: UNA REVISIÓN SISTEMÁTICA

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ABSTRACT

Objective: to identify the communication strategies that promote the humanization of health care provided to adult/older adult patients hospitalized at the end of life. **Method:** systematic review carried out with primary studies from EBSCO, PubMed, CINAHL, MEDLINE, LILACS, Web of Knowledge, and B-On databases, and SciELO and Cochrane digital libraries, between November 2012 and January 2013, selected according to the PIOS method, from the following question: What are the communication strategies that promote the humanization of health care in the interaction between nurses and adult/older adult patients at the end of life? **Results:** the articles selected demonstrated the urgent need to acquire specific skills in the field of communication, in order to promote a dignified end of life. **Conclusion:** regardless of experience, or even the ability to deal with the proximity of death, it is extremely important to develop strategies that are not exclusively based on verbal expression, but also on nonverbal signals, in order to promote a positive health care experience. **Descriptors:** Communication; Nonverbal Communication; Humanization of Health Care; Terminal Patient.

RESUMO

Objetivo: identificar as estratégias comunicacionais promotoras da humanização do cuidado ao paciente adulto/idoso hospitalizado em fim de vida. **Método:** revisão sistemática resultante da pesquisa de estudos primários nas bases de dados EBSCO, PubMed, CINAHL, MEDLINE, LILACS, Web of Knowledge, B-On e nas bibliotecas virtuais SciELO e Cochrane, entre novembro de 2012 e janeiro de 2013, selecionados de acordo com o método PIOS, a partir da seguinte questão: Quais são as estratégias comunicacionais promotoras da humanização dos cuidados na interação enfermeiro-pessoa adulta/idosa em fim de vida? **Resultados:** os artigos selecionados evidenciam a necessidade premente de adquirir competências específicas na área da comunicação, para que se possa promover um fim de vida digno. **Conclusão:** independentemente da experiência, ou até mesmo da preparação para lidar com a proximidade da morte, revela-se extremamente importante desenvolver estratégias que não passem exclusivamente pela expressão verbal, mas também pelos sinais não verbais, de forma a promover uma experiência de cuidado positiva. **Descritores:** Comunicação; Comunicação Não Verbal; Humanização da Assistência; Paciente Terminal.

RESUMEN

Objetivo: identificar las estrategias de comunicación que promuevan la humanización de la atención al paciente adulto/adulto mayor hospitalizado en el final de la vida. **Método:** revisión sistemática llevada a cabo con estudios primarios de las bases de datos EBSCO, PubMed, CINAHL, MEDLINE, LILACS, Web of Knowledge y B-On, y en las bibliotecas virtuales SciELO y Cochrane, entre noviembre de 2012 y enero de 2013, seleccionados según el método PIOS con la siguiente pregunta: ¿Cuáles son las estrategias de comunicación que promueven la humanización de la atención en la interacción entre enfermeros y adultos/adultos mayores en el fin de la vida? **Resultados:** los artículos seleccionados demuestran la urgente necesidad de adquirir habilidades específicas en el área de comunicación, con el fin de promover un final de vida digno. **Conclusión:** independentemente de la experiencia, o incluso la habilidad para lidiar con la proximidad de la muerte, es extremadamente importante desarrollar estrategias que no se basen exclusivamente en la expresión verbal, sino también en las señales no verbales, para fomentar una experiencia positiva de cuidados. **Descritores:** Comunicación; Comunicación No Verbal; Humanización de la Atención; Paciente Terminal.

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INTRODUCTION

The end-of-life process is usually associated with feelings of loss, pain, and suffering. In addition to the experience of pain, which is regulated by a set of organic factors, it is known that diseases cause other problems that bring a particular type of suffering to the patients and their families, not just representing something physical, but also implying cognitive, emotional, and even cultural aspects.

In face of this problem, the humanization of health care is a current and growing requirement that emerges from our realities in hospital contexts, in which the requirement for handling high-tech equipment causes some obstacles to the practice of humanized care, therefore affecting the relationship between health professionals, patients, and their families.¹

Health care based on the incessant search for human dignity is essential in the face of a reality that is individual, complex, and unique, representative of suffering. For the sake of health care humanization, communication is an important tool for the sustainability of nursing interventions, since it encompasses all forms of exchange of ideas, feelings, and emotions. In this context, the main challenge will be the personal involvement of nurses with the patients by combining science and humanism. In this way, the patients will be understood as a whole, the bearer of a terminal disease who lacks active and rigorous care.

Even though symptomatic control is strictly recognized in the health care provided to patients at the end of life, our attention must also focus on communication, the strengthening of interpersonal relationships, and the collaboration with the patients in the search of a meaning of life. The integration of the physical, psychological, and spiritual aspects of treatment should be sought so that the patients can adapt themselves to their condition in a complete and constructive way.²⁻³

Communication is always present in the individuals we care for, either by their own glance, face expression, gestures, words, and even the way in which they occupy their environment. In the case of terminal patients, communication codes are different, because we are both in the presence of patients who wait for a sign in our attitude, our form of expression, and who are so weakened that speak little or nothing. In such circumstances, we just count on nonverbal communication, through which we can identify a set of

valuable information that confirm the congruence between acting and feeling in the relationship between patients and health professionals and demonstrate interest, empathy, and appreciation of the patients.⁴

Although perceiving and listening to the others is considered important and necessary, we should also learn what happens inside ourselves, being able to identify the emotions and/or reactions that words cause in ourselves. In this context, Phaneuf affirms that "[...] communicating is to be in a relationship with the other, maintaining the relationship with oneself".^{5:22} This implies that regardless of the way we communicate, we should consider some elements essential for an efficient communication, such as patience, transparency, security, and even a suitable didactic competence.⁶

Three levels of communication that nurses may develop along the patients on a daily basis are: a) "daily interactions", including conversations that discuss key issues of treatment and the satisfaction of personal care; b) "assessment of treatments", in order to control pain and suffering; and c) the level described as "existential", which occurs in the deepest sense of the patients.⁷ This sensitive and subtle level of communication includes the existential issues of the end of life.

In fact, in order to care for each person, it is essential to build a relational process that takes into consideration their experiences, in which sincerity, spontaneity, availability, respect, and unconditional acceptance are the cornerstones for establishing a relationship of trust and the relief of suffering.⁸

Given the above, it is noted that man's end of life has an inestimable value that is no less than any other value in another stage of human life, a reason why a greater humanization of care is crucial. This humanization requires a reflective process regarding the assumptions that guide the professional nursing practice, with respect for the requirements, ethical values, and moral principles, and the relief of pain and suffering, through available technological and psychological resources.

METHOD

In the development of this systematic review, we considered communication, humanization, and patients hospitalized at the end of life as the main issues, in an association from which the following research question emerged: "What are the communication strategies that promote the humanization of health care in the interaction

between nurses and adult/older adult patients at the end of life?”. This question is particularly related to the need to seek some scientific evidence substantiating all our actions when we are, on a daily basis, confronted with issues and decision making related to effective practices at the end of life.

In this way, the purpose is to answer other questions with regard to end-of-life communication: Is the way we communicate an expression of a more humanized care? What is the meaning attributed by the patient to verbal and nonverbal communication? How does communication reduce the pain and the anguish of the patients at the end of life? Do nurses appreciate the interpersonal communication in the context of health care provided to patients at the end of life?

From these questions and seeking knowledge that justify and organize our actions, we will proceed to present the method used and the results found. In order to acquire the current knowledge about

communication strategies, necessary for a more humanized care provided to patients at the end of life, we sought to integrate data and information covered in a set of studies conducted recently.

The main goal was to identify the communication strategies for promoting the humanization of care provided to adults/older adults at the end of life in hospital contexts. The survey was carried out from November 2012 to January 2013 by two reviewers—the authors—using English and Portuguese languages. Initially the date was restricted to 2009; however, due to some difficulties in finding articles that comply with the criteria laid down, the search was extended to 2006.

For the search of the relevant empirical studies, based on the question stated, the following specific keywords were used: communication; nonverbal communication; health care humanization; terminal patient.

Participants	Nurses and other health professionals. Patients hospitalized at the end of life.	Keywords: communication; nonverbal communication; health care humanization; terminal patient; terminally ill.
Interventions	Verbal and nonverbal communication strategies.	
Comparisons	Does not apply.	
Outcomes	Communication strategies for promoting the humanization of health care. Needs for professionals' training.	
Study design	Quantitative and Qualitative.	

Figure 1. Protocol of assessment

The databases used were: EBSCO; PubMed; CINAHL; MEDLINE; LILACS; Web of Knowledge; and B-On, and the digital libraries were SciELO and Cochrane, after having related the question previously defined in terms of population, interventions, outcomes, and study design. As a complementary source, a manual search of journals was carried out in

the Library of the Portuguese Catholic University.

In order to carry out the research and acquire the most appropriate articles/studies to answer the research question and in accordance with the goals of our review, a set of inclusion and exclusion criteria were established, presented in Figure 2.

Criteria for participants selection	Inclusion criteria	Exclusion criteria
	<ul style="list-style-type: none"> - Adult/older adult patients hospitalized at the end of life. - Nurses responsible for providing health care. - Health professionals carrying out activities in hospital institutions. 	<ul style="list-style-type: none"> - Patients hospitalized in intensive care units and urgency/emergency services, since these are acute care settings with very particular characteristics. - Studies conducted in Nursing Homes, since there are not such structures in Portugal. - Pediatric patients. - Exclusively physicians' perceptions.
Intervention	<ul style="list-style-type: none"> - Importance of communication as expression of a more humanized end-of-life care provided to patients. - Nurses' communication skills for providing end-of-life care to patients. 	
Design	<ul style="list-style-type: none"> - Empiric studies with qualitative or quantitative approach. 	<ul style="list-style-type: none"> - Systematic review of literature, theses and dissertations.

Figure 2. Inclusion and exclusion criteria for empiric studies.

Regarding communication as an intrinsic need to our existence and relationships, it is important to understand it in the light of the interaction between patients and nurses/caregivers. For this reason, we excluded studies, in which there was no evidence of interpellation between the caregivers. However, since teamwork is one of the foundations of palliative care, it made sense to consider studies where, in addition to the nurses, there was collaboration on the part of other health professionals (physicians, nutritionists, physiotherapists).

Still, it was considered relevant to exclude the contexts of intensive care and urgency, since they are highly technological services with therapies often aggressive in those situations, which give rise to some ethical questions. In addition, the ability of these patients to communicate may be jeopardized by the need for ventilatory support or even sedation, which would require a different approach.

A significant number of studies were excluded, since, above all, they had been conducted in Nursing Homes, moving away from the Portuguese reality, as well as those very frequently conducted in intensive care units. In addition, a considerable number of studies devoted to pediatrics were excluded, because adult or older adult patients were less mentioned. Studies whose main participants were physicians were also excluded, because these studies are often associated only with the communication of bad news, rather than the communication/relationship with the patient at the end of life.

In the selection of articles, we sought to assess: whether the inclusion and exclusion criteria were appropriate; the quality of the

studies included; whether the results had been systematically combined; and whether the conclusions were substantiated by data.¹⁰

Therefore, the studies considered were those that complied with the inclusion criteria. Of a total of 182 articles, 19 were considered relevant to our study. After reading the abstract and complying with the relevant criteria, 11 articles were excluded. With the integral reading, eight articles were accepted (primary sources), which are presented in Figure 3.

The selection of articles was carried out in accordance with the assessment matrix proposed by a recent publication,⁹ which ranks the quality of evidence into seven levels: I - the evidence is derived from systematic review or meta-analysis of controlled randomized clinical trials or from clinical guidelines based on systematic reviews of controlled randomized clinical trials; II - evidence derived from at least one well delineated controlled randomized clinical trial; III - evidence obtained from well delineated non-randomized clinical trials; IV - evidence from cohort studies and well delineated case-control studies; V - evidence from systematic review of descriptive and qualitative studies; VI - evidence from a single descriptive or qualitative study; and VII - evidence from authorities' opinion and/or reports of committees of experts. Regarding the methodological design, three studies were descriptive non-experimental quantitative, four were qualitative, and one had a mixture of methods, with evidence level 6, not reaching the highest level of qualification.

Primary studies	Participants	Objectives	Intervention and method of analysis
Clarke A, Ross H. ¹¹ (2006) United Kingdom	Intentional sample: 24 nurses (10 worked in a palliative care unit and 14 in a medical service).	To explore nurses' perceptions and experiences related to the communication with older adults at the end of life.	Qualitative study (exploratory). Focal groups.
Liu Jun-E, Mok Esther, Wong Thomas. ¹² (2006) China	Convenience sample: 20 oncology patients selected from two hospitals of Beijing that met some inclusion criteria: being aware of cancer diagnosis; having been hospitalized for at least two weeks; and who had no difficulty in verbal communication.	To understand patients' perceptions and experiences related to communication as an attitude composing nursing care.	Qualitative study (content analysis). Semi-structured interviews.
Araújo M, Silva M. ¹³ (2007) Brazil	39 oncology patients with no cure prognosis, submitted to palliative chemotherapy, hospitalized at a private hospital institution.	To know patients' expectations regarding the communication with the nursing team.	Qualitative study (exploratory and descriptive). Semi-structured interviews.
Afonso H, Lourenço S. ¹⁴ (2011) Portugal	11 nurses (seven females and four males) having provided care to patients at the end of life for more than a year.	To assess the strategies used to humanize health care provided to terminal patients.	Qualitative study (exploratory). Semi-structured interviews.
Boyd Denise et al. ¹⁵ (2011) United States	31 oncology nurses.	To characterize nurses' attitudes in the final three months of patients' lives.	Quantitative study (descriptive and correlational). Application of a questionnaire with close and open questions.
Araújo M, Silva M. ¹⁶ (2012) Brazil	Non-randomized and convenience sample: 303 health professionals providing care in health institutions.	To assess the relevance and use of communication strategies for palliative care.	Quantitative study (descriptive, exploratory and cross-sectional). Application of questionnaires.
Kozłowska L, Doboszynska A. ¹⁷ (2012) Poland	95 nurses working at five hospices in Poland aged between 21 and 65 years old, and 21% had specific training in palliative care.	To assess the communication strategies most used by nurses in the interaction with the patients at the end of life.	Quantitative study (descriptive statistic). Application of questionnaires.
Reynke LF. et al. ¹⁸ (2012) United States	717 nurses from four U.S. states (working in hospitals or that had already worked for more than 19 years).	To know nurses' perspectives regarding important nursing knowledge, though underused for end-of-life care.	Qualitative and quantitative study. Assessment of interviews and questionnaires.

Figure 3. General characteristics of the studies composing the literature sample.

ANALYSIS OF THE RESULTS

Through the literature review, we assessed and reflected on the articles selected on the basis of the research question and the goals of

the study. Eight articles were assessed, of which four were qualitative, three quantitative, and one integrated both types of approaches (Figure 4).

Primary studies	Findings
11	This article reports the main factors influencing nurses' communication with older adults at the end of life: 1 - nurses' perceptions and experiences: speaking and listening to older adults about the end of life; 2 - the development of skills and understanding - "learning to listen"; 3 - the "culture of caring": to explore the things that patients want to do before they die and help them plan. Finally, the studies highlight that the own experience and the collaboration of the team help respond sensitively to the concerns of ill persons.
12	Three main topics emerged from the data obtained: nurses' attitudes of affection and their responsibility for providing emotional support; professional knowledge; and professionals' ability to provide information and practical support. This study underlines that nurses' compassionate attitude toward patients' suffering has a strong impact, especially when the patients are very depressed. The studies identified the valuable help of the informative support to cope with and adapt to their diseases and lessen their feelings of helplessness. For these patients, receiving information implies that: their current situation is clarified; they receive suggestions; each procedure is explained in advance; and their questions are clearly answered. As a result of nurses' professional knowledge and proficiency to provide emotional, informative, and practical support, patients found that: they had better feelings; they were less depressed; and they were able to establish a trust relationship with the nurses who cared for them.
13	Four categories emerged from the respondents' discourses: interpersonal communication (the company, being together), which was considered an important attribute for the end-of-life care provided to the patients, with importance given to nonverbal signals of nurses (eye contact, smile) for the establishment of a trust relationship. They highlighted the need for a compassionate presence that provides comfort and does not focus the relationship only on disease and death, and finally, the appreciation of cheerful verbal communication, which emphasizes the optimism, the conversation and good mood as a way to ease the tension in a context of pain and suffering.
14	The main strategies for humanizing end-of-life care mentioned by the nurses engaged in the assessment were: verbal and nonverbal communication (attitude, glances, serenity or anxiety, mood, respect, and attention), as well as building an empathetic relationship between nurses, patients and their families, based on respect for human dignity, understanding, and appreciation of the person as a whole.
15	Most nurses stated that they communicated with the families rather than with the terminal patients. The study also shows that physicians or nurses are who usually begin the conversation and exceptionally the patients. However, patients make the final decision about receiving care and the importance of being informed about their prognosis is recognized. The practice most frequently used was active listening. Aromatherapy and guided imagination were the least used.
16	According to this study, the verbal strategies most commonly used were asking the patients whether they were aware of their condition/disease and how they felt. The nonverbal strategies most mentioned were affective touch (hug, kiss on the cheek, caress their hair, firm handshake, and touching hands, arms or shoulders), glances and smiles, showing interest, and physical proximity in the construction of an empathic relationship. A fifth strategy was highlighted, which joined verbal and nonverbal signals, i.e., listening actively. Finally, they considered that professionals' training was urgent with respect to the use of communication strategies for interacting with terminal patients.
17	This study found that 41% of the nurses communicated through nonverbal signals, the most used forms being touching, facial expression, and eye contact. On the other hand, 93% of the nurses considered that they could express compassion through nonverbal communication (holding the patients' hands, silently making company, smiling at the patients, and keeping eye contact). Only 23% stated that they interacted with the patients through verbal contact. The importance of nurses' image was also mentioned, because the patients paid attention to these aspects. Finally, 94% of the nurses recognized the importance of acquiring knowledge and training in the field of communication, in order to be skilled to deal with these patients.
18	Of the 54 items developed, five domains were classified: communication skills; technical skills; affective skills; respect for the patients' values; and patient-centered care system. The nurses considered the communication skills as extremely important—though still little present in practice—since there was a strong discomfort in talking about death. They regarded communication as a key element to provide quality care, recognizing the need for educational programs.

Figure 4. Findings of the studies that composed the literature sample.

Communication emerges as one of the central objectives of end-of-life care, in order to achieve a quality and humanized service.¹⁹ However, a need clearly evidenced by scientific studies—although still poorly carried out in palliative care units—is training/education of communicational attitudes.^{4,16-18,20-21} It is extremely important to sensitize professionals who deal with these patients to the need to establish authentic and sincere relationships, full of meaning and human warmth. It is an easy task and involves availability and attention, and ability to correctly interpret the message, in order to achieve the intended impact.^{4,11} Proper training of these skills produces effective and lasting changes in the professional

performance, increasing the satisfaction of patients and their adherence to treatments.^{8,12}

Some barriers pointed out with respect to the ineffectiveness of communication are justified by the environment and organizational issues. These obstacles refer to lack of time and privacy, some reluctance to start the topic due to medical hierarchy, or little knowledge about issues related to the end of life and the lack of skills for communicating these topics.^{8,11}

To overcome these difficulties, building an empathic relationship, with emphasis on communication, emerges as the main strategy to humanize nursing care.¹⁵ This relationship should be characterized by an interactive and

customized process, which includes affinity, understanding, and acceptance between nurses and patients.

Studies show that nurses, by being empathetic, allow the patients to express their stress and satisfy their psychological needs, in addition to recognizing the impact that the compassionate attitude of nurses has on most depressed patients.¹²⁻¹³ These studies also affirm that the concern with communication extends to the information given and to careful listening, that gives us the conviction that the message is received.^{4,12,16}

Therefore, active listening is considered one of the main work instruments for palliative care, because through it we can identify the needs in the different dimensions of those who experience this process.¹⁵⁻¹⁶ Active listening includes: the use of silence; conscious facial signals, that show interest in what is being said; and assuming an attitude of solidarity and responsibility, taking into account the physical approach and the position of the body (trunk turned toward the patient). In addition, the use of short verbal expressions should be taken into account, such as "I'm listening", "go on", "and so", as well as performing important caring actions: active greeting; friendly attitude; affection; understanding; talking face-to-face and with a soft voice; and smiling, in order to give them the strength to fight.^{12,16}

Cheerful verbal communication that focuses on optimism and good mood is chosen as an important strategy to relieve the tension in a context of pain and suffering.¹³ Other aspects still valued are: providing information to the patients at the end of life, so that they can understand their disease process; talking with honesty and directly; showing availability and sensitivity when these patients address the issue of death, exploring with them the things they want to do before dying and collaborating in the achievement of their goals.^{11,18}

Since one of the purposes of communication is to reduce uncertainty and

improve the relationships, it is also relevant to appreciate the nonverbal aspects of communication, namely: serenity or anxiety; facial expression; eye contact; smiles; and touching, through which the sense of isolation can be reduced.^{2,13-4,16-7}

Silence is another fruitful moment of the relationship, and never a synonym of emptiness.⁴ In most cases, difficult moments have to be faced; however, for patients at the end of life, communication performed through the presence and silence acquires a special significance, since it may be interpreted as a sign of a true company full of deep respect.¹⁶

Most nurses emphasize that holding hands is a way to express emotions and smiling is a form of tension relief in difficult moments, this way facilitating dialogue and making patients more satisfied.¹⁷ In fact, patients were very sensitive to nonverbal communication, recognizing that it significantly influenced their mood. On the other hand, nurses, by being empathetic, allowed them to express their stress and satisfy their psychological needs.¹²

Several studies emphasize distinctly nurses' profiles to provide quality care, making them responsible for applying knowledge and skills of nonverbal communication, which enable them to decode the essential information and thereby lessen the anxiety of the patients at the end of life. Sometimes, these patients request things or actions hard to be understood, hence the desire to establish an interpersonal interaction through gestures, attitudes, facial expression, bodily movements, among other particularities that meet their needs.^{12-3,16}

In addition, they consider important to make the patients feel that in the proximity of death they will not be alone. However, to that end, there must be an effective communication between the multidisciplinary team for the patients' quality of life.¹⁸ Undoubtedly, the use of communicative strategies constitutes the center of emotional support in the end-of-life care, such as presented in Figure 5.

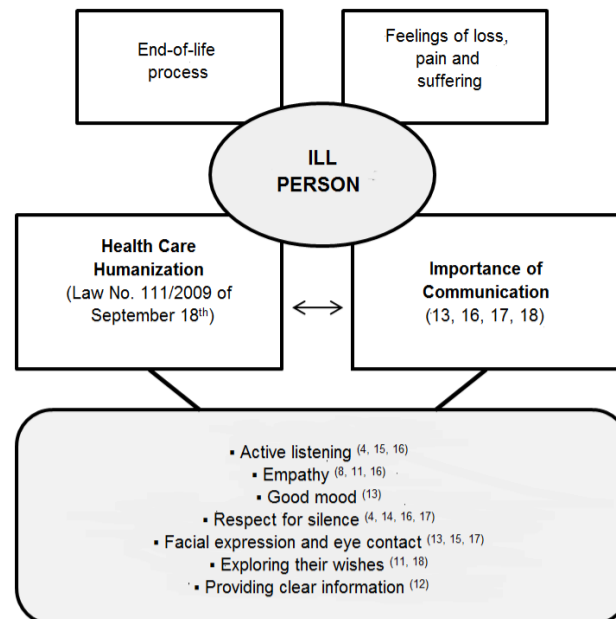


Figure 5. Importance of communication in care provided to end-of-life patients.

Skills such as listening, questioning, exploring feelings, and feedback are essential and necessary tools to provide emotional comfort and positively influence the patient's psychological adjustment to their new situation, losses, and uncertainty, which are characteristic aspects in an end-of-life context.

Corroborating with the various studies, communication emerges as a basic tool in the construction of strategies that promote the humanization of care and that assumes respect for silence, the use of plain language, a smile that expresses confidence, a reassuring glance, warm touch that provides support and comfort, and a word of encouragement, able to raise the self-esteem of the patients.

CONCLUSION

By assessing these articles, we found that all of them highlighted communication as a pressing need at the end of life. We believe that the dimension of terminal patients' suffering demonstrates the need to develop a scientific and humanized care, able to allow the institutions and health professionals to give an efficient response to these patients, because among the most important tools in palliative care are words and listening. Moreover, given that the establishment of a positive relationship with patients only becomes possible through effective communication, it is essential to take into account some criteria that can jeopardize the communication, and also consider the need for specific training.

Nurses stay longer with the patients and have greater proximity and availability regarding the needs expressed by these patients at the end of life. Therefore, investing in the field of communication,

rather than a challenge, is a current requirement of our care process. Communication between patients at the end of life and their care providers is a priority. Caring for patients with advanced diseases is an integral part of nursing practice and requires a certain level of interpersonal involvement. Thereby, nurses are continually challenged to reflect not only on their experiences with patients, but also on their own actions, behaviors, values, and beliefs. This reflective process, supported by scientific evidence, will help us develop abilities to communicate with these patients and look at them as humans, allowing them to feel valued, at the same time that we provide a more humanized care to them.

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