INTEGRATIVE LITERATURE REVIEW ARTICLE

COMMUNICATION TOWARDS THE TERMINALITY PROCESS: INTEGRATIVE REVIEW

A COMUNICAÇÃO DIANTE DO PROCESSO DE TERMINALIDADE: REVISÃO INTEGRATIVA

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ABSTRACT

Objective: to know how literature has addressed communication in palliative care and its influence on the patients' treatment and life. Method: this is an integrative review which included scientific papers published within the period from 1993 to 2011 on the Virtual Health Library database. Among the 89 papers, 14 were selected. Data were analyzed and distributed into three categories, according to the content analysis: 1) the communication as a challenge in palliative care; 2) the influence of communication on the quality of care; 3) know the barriers in the communication process with the terminal patient. Results: the importance of communication to provide palliative care was highlighted, the difficulties for establishing an effective communication, besides the lack of professional training to talk about death and the need for investment. Conclusion: the challenge is introducing in the undergraduate courses the communication process as a tool for nursing work, aiming to promote the establishment of meaningful relationships between students, nurses, patients, and relatives. Descriptors: Communication; Palliative Care; Nursing.

RESUMO

Objetivo: conhecer como a literatura tem abordado a comunicação em cuidados paliativos e sua influência no tratamento e na vida dos pacientes. Método: trata-se de revisão integrativa que incluiu artigos científicos publicados no período de 1993 a 2011 nas bases da Biblioteca Virtual em Saúde. Dentre os 89 artigos, foram selecionadas 14. Os dados foram analisados e dispostos em três categorias, de acordo com a análise de conteúdo: 1) a comunicação como desafio nos cuidados paliativos; 2) a influência da comunicação na qualidade do cuidado; 3) conhecer as barreiras no processo de comunicação com o doente terminal. Resultados: a importância da comunicação na realização de cuidados paliativos foi destacada, as dificuldades para estabelecer uma comunicação efetiva, além do despreparo do profissional para falar da morte e da necessidade de investimento. Conclusão: o desafio é introduzir nos cursos graduação o processo comunicativo como instrumento do trabalho de enfermagem, visando a promover a formação de relações significativas entre alunos, enfermeiros, pacientes e familiares. Descritores: Comunicação; Cuidados Paliativos; Enfermagem.

RESUMEN

Objetivo: conocer como la literatura ha abordado la comunicación en cuidados paliativos y su influencia en el tratamiento y la vida de los pacientes. Método: esta es una revisión integradora que incluyó artículos científicos publicados en el periodo de 1993 hasta 2011 en las bases de la Biblioteca Virtual en Salud. Entre los 89 artículos, 14 fueron seleccionados. Los datos fueron analizados y agrupados en tres categorías, según el análisis de contenido: 1) la comunicación como desafío en los cuidados paliativos; 2) la influencia de la comunicación en la calidad de la atención; 3) conocer las barreras en el proceso de comunicación con el enfermo terminal. Resultados: la importancia de la comunicación en la realización de cuidados paliativos se destacó, las dificultades para establecer una comunicación efectiva, además de la falta de preparación del profesional para hablar de la muerte y la necesidad de inversión. Conclusión: el desafío es introducir en los cursos de graduación el proceso comunicativo como instrumento del trabajo de enfermería, con el propósito de promover la formación de relaciones significativas entre alumnos, enfermeros, pacientes y familiares. Descriptores: Comunicación; Cuidados Paliativos; Enfermería.
The increase in nursing research has demonstrated the need for the profession to face the complexity of health care and follow up technological and scientific advances in the field to favor the quality of care provided and the construction of scientific knowledge. In this context, the search for a humanized practice and the inclusion of palliative care in the professionals’ routine stand out. The World Health Organization (WHO) defines palliative care as active and total care for the patient without any cure possibility. This care is differentiated, with the aim of improving the patients and their relatives’ lives, through the evaluation and relief of symptoms and pain, as well as the offer of psychosocial and spiritual support to patients.

Among the pillars of palliative care one emphasizes communication, which is more than simply providing some information. Communicating requires the individuals’ involvement so that there’s information exchange, mutual understanding, support, and coping of difficult and painful issues. Moreover, an effective communication requires time, commitment, and the sincere desire to listen to the other person’s concerns, providing answers where they don’t exist or just being with the person where she/he is and showing to be an empathetic presence with regard to her/his pain.

Despite all scientific and technological advances, cancer is still one of the most dreadful diseases, regarded as a death sentence, leading the patients and relatives to feel the need to cope with problems about which nothing used to be said. This difficulty for talking about the issue isn’t observed only in patients and relatives, but also in health professionals. Even in the face of so many difficulties, little emphasis has been directed towards training involving communication techniques and skills, and in most cases the professionals depend on their personal experience and judgment regarding the decision to inform the patient about her/his illness, as well as the best way and the best time to do that.

The patient with no therapeutic possibility is rarely unaware of her/his status, due to signs that the body itself presents, but she/he often isn’t able interpret these signs, something which causes fear and anguish. Under these conditions, it’s usual for patients to resort to health care professionals, people theoretically qualified to give some explanation, but they aren’t always able to communicate clearly and objectively with regard to the disease. Avoiding the subject, or even don’t tell the truth, are attitudes which don’t mask the signs, they just make the patient more anxious and distressed due to the situation. Although one thinks that avoiding the truth corresponds to keep the patient at rest and tranquility, this behavior actually ends up contributing to make the patient even more anxious, distressed, and afflicted due to even more atrocious doubts.

Therefore, one regards effective communication as a key element for establishing a care relationship. It’s worth remembering that adequate communication is that which is most appropriate to a given situation, person, or time, besides reaching a previously defined goal; so, there’re no rules to establish effective communication, but someone who communicates and someone who receives information and understands it.

This study is justified by the need to emphasize communication as a key nursing tool, since it significantly contributes to the development, planning, and implementation of a higher quality of care.

Given the above, this study aims to know how the literature has addressed communication in palliative care and its impact on the patients’ treatment and lives.

### Method

This study consists of an integrative review of the scientific literature, technical, which, through the synthesis of multiple published studies, allows one to achieve conclusions on a certain theme by applying systematic and organized methods and it contributes to deepen knowledge on the theme under study.

In order to strictly comply with its stages, in this integrative review the steps described below were adopted.

- **Step 1:** establishing the hypothesis or research question;
- **Step 2:** establishing the inclusion/exclusion criteria, choosing database, and selecting the material to be searched for;
- **Step 3:** extraction of information, organization and preparation of the database;
- **Step 4:** evaluation of studies, inclusion/exclusion of studies and critical analysis;
- **Step 5:** discussion of data identified, recommendations and suggestions for future research;
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- Step 6: summary of evidence or presentation of the review.

The central theme of this study is “communication in palliative care”, and the research questions are: 1) “What is the approach brought by the study concerning communication in palliative care?”; 2) “What is the importance of communication in palliative care?”.

The electronic databases selected were the Virtual Health Library (VHL), using the following descriptors: palliative care, nursing, communication, oncology, and neoplasia, standardized by the Health Sciences Descriptors (DeCS), as well as their counterparts in English and Spanish. The inclusion criteria were the fact that papers were written in Portuguese, English or Spanish, and that the papers are currently available in full text and indexed in the databases mentioned above. The publication period was initially defined in ten years, however, due to the low number of papers addressing this theme, it was extended to 18 years – from 1993 to 2011. All papers which met the inclusion criteria were analyzed.

For organizing the information identified, a spreadsheet was prepared in the software Microsoft Office Excel containing the following information: title, publication year, location where the study was carried out, study type, journal, objective, results, question 1 and question 2.

After analyzing the studies, the papers which didn’t meet the inclusion criteria were excluded, as well as those repeated. For discussing the data identified, there was a need for, after step four, conducting a reading of papers, including only those which contained evaluation, analysis, and discussion regarding communication in palliative care.

This study was based on categorical content analysis, which deals with the meaning of words, aiming to know psychological, sociological, historical, and other kinds of variable, through deduction mechanisms based on indicators constructed from a sample of private messages, which work as simple meaning units.11

The content analysis was developed according to the phases of pre-analysis, material exploration, and processing and interpretation of results. In the first phase, or pre-analysis, detailed readings of papers were conducted, in order to survey the points relevant to the study objective. In the second phase, material exploration, the data were codified, a process by which the raw data are systematically processed and aggregated into units. In the last step, the processing and interpretation of results, a categorized was performed, which consists in the classification of elements according to their similarities and differences, with subsequent regrouping due to common characteristics.

The analyzed data were arranged into three categories: 1) Communication as a challenge in palliative care; 2) The influence of communication on the quality of care; and 3) Knowing the barriers in the communication process with the terminally ill patient.

RESULTS AND DISCUSSION

The initial sample of this review consisted of 89 articles found in the VHL, out of which 32 were excluded due to be repeated, 14 because they aren’t available in full text, and 29 because they don’t provide an answer to the guiding questions established by this study. After carefully following the steps of an integrative review, the 14 papers which met the inclusion criteria were analyzed; they’re represented in Figure 1.
Studies, published in international journals, were published in each of the years 2007, 2009, 2010 and 2011; only one paper was published; in 1993, 2005, and 2008, only 1 paper was published. The study shows a large participation of Nursing, since in 7 out of the 14 publications all authors are nurses; the authors of the other papers are psychologists and physicians. Regarding the journals, 11 papers were published in national journals, and, out of these, 5 in Nursing journals, 3 in the same journal; and the others were published in international journals.

Figure 1. Distribution of selected papers according to authorship, title, and source. The analysis of papers enabled the survey of relevant information. Out of the 14 publications included in the study, 8 are descriptive and exploratory and approach communication between the team and the patient, besides presenting the cultural context of death and mourning care; 3 are review studies, which aim at improving palliative care and communication; and 3 are qualitative and report the eases and difficulties of communication.

Regarding the publication year, 2 papers were published in each of the years 2007, 2009, 2010, and 2011; in 2006 3 papers were published; in 1993, 2005, and 2008, only 1 paper was published. The authorship of the papers has a large participation of Nursing, since in 7 out of the 14 papers all authors are nurses; the authors of the other papers are psychologists and physicians. Regarding the journals, 11 papers were published in national journals, and, out of these, 5 in Nursing journals, 3 in the same journal; and the others were published in international journals.

The selected papers are presented in Table 1, with the relevant information surveyed during analysis, such as goals, methods, and main results.
<table>
<thead>
<tr>
<th>Identification</th>
<th>Objective</th>
<th>Methods</th>
<th>Main results</th>
</tr>
</thead>
<tbody>
<tr>
<td>E1</td>
<td>Check the psychologist’s work in an interdisciplinary team in the palliative care proposal</td>
<td>Interview with healthcare professionals from a public hospital in São Paulo, performing Bardin’s content analysis.</td>
<td>The team lists as easies of communication openness to dialogue, respect to the other person’s role, and mutual help. It also highlights as a difficult dealing with life’s finiteness.</td>
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<td>E2</td>
<td>Focusing on the issue of the terminally ill patient’s rights and duties through the three principles of bioethics: autonomy, beneficence, and justice.</td>
<td>Author’s reflection.</td>
<td>One points out the patient’s right to know the truth about her/his status, dialogue, be heard, and have answers. One points out the patient’s autonomy with regard to the freedom of choice, whereas in the terminal stage the patient’s will should be taken into account.</td>
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<td>E3</td>
<td>Explore mourning and the importance of providing information and support at the right time to the right people.</td>
<td>One describes a project to develop a path to care for mourning and the bridge between the hospital sector and the community.</td>
<td>One presents the importance of communication with the patient and family, in a clear manner, supporting them with regard to difficulties, and always respecting their beliefs, religions, values, cultures. One emphasizes the importance of monitoring bereaved families.</td>
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<td>E4</td>
<td>Describe a graduate program in palliative care nursing.</td>
<td>Evaluation of the teaching plan inspired by the students’ learning process.</td>
<td>One presents a program with a holistic view on human care and communication. One encourages different learning models in the activities performed by students.</td>
</tr>
<tr>
<td>E5</td>
<td>Check whether communication is an effective intervention in palliative care.</td>
<td>Interview with 21 palliative care providers, through an educational intervention to improve communication about end of life.</td>
<td>Effective communication results in a more positive experience in health care both for the patient and family.</td>
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<td>E6</td>
<td>Highlight the communication gaps found in hospital-driven care models which pay attention to the importance of symbolic exchanges.</td>
<td>One describes the health organizations as linguistic communities based on the conceptual framework of Habermas’s communicative action theory.</td>
<td>Palliative care procedures are regarded as emblematic communicative models, dedicated to mutual transdisciplinary collaboration. Thus, the linguistic interaction with patients and their relatives provides the health care teams with a basis.</td>
</tr>
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<td>E7</td>
<td>Identify the criteria which the health team uses to classify a patient as terminally ill, and also know what feelings are generated by the same team towards death. Study how the health care teams define and experience the inter-relation with the terminally ill patient.</td>
<td>Ethnographic research. Semi-structured interviews with physicians and nurses, which underwent content analysis.</td>
<td>One notices health professionals’ difficulty and fear to classify a patient as terminally ill, as they don’t know yet what a terminally ill patient is, yet. The health care field have doesn’t prepare the professionals to deal with death. When it isn’t overcome, it brings a sense of failure, marking the professional’s life and making the terminally ill patient is regarded as a symbol of defeat.</td>
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<td>E8</td>
<td>Evaluate the current status of knowledge on terminal illness and palliative care in the ICU, identify key issues, and suggest a research agenda about these issues.</td>
<td>Bibliographic review.</td>
<td>Adequate communication was considered of paramount importance for conducting the treatment of a terminally ill patient. One suggests the suitability of not futile treatments, focusing on pain and symptom control, respect with regard to the individual needs and desires, and continuing education programs on palliative care for the professionals.</td>
</tr>
<tr>
<td>E9</td>
<td>Highlight the importance and need to better understand the dimensions of human life, stressing the dimension of care for pain and human suffering.</td>
<td>Bibliographic review.</td>
<td>Our health care system is negligent with regard to palliative care. The philosophy of palliative care is concerned with quality of life, value of life, and meaning of life. As we were helped to be born, we must also be helped at the farewell moment.</td>
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<td>E10</td>
<td>Check what is adequate communication for the nursing team with regard to the perception of the critical patient’s relatives.</td>
<td>Interview with 13 relatives of hospitalized patients, using content analysis.</td>
<td>Adequate communication is that in which the information presented is clear and objective, solving doubts and providing guidance. Communication is a way to make care more humanized.</td>
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<td>E11</td>
<td>Check whether the nurse is able to identify the five stages of the dying process, as described by Kübler-Ross and Individual interview with 13 nurses, analyzed according to content analysis.</td>
<td>One found out that 92% of nurses were able to identify at least one stage of the dying process in their experience with terminally ill patients. Check the...</td>
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Figure 2. Objectives, methods, and main results of the selected papers.

There were various objectives in the studies carried out, and all concerned the importance of communication to the achievement of palliative care. Out of the studies analyzed, 8 emphasize communication as a major factor for a good quality care; but only 3 point out the difficulties found for establishing an effective communication and only other 3 stress the professional’s lack of training to talk about death and the need for investment in this regard.

These findings may reveal that professionals have awakened to the need for further discussion on the theme, since communication is a key tool for implementing a good quality care.

Through thematic content analysis, one could identify the categories indicated and defined below.

♦ Communication as a challenge in palliative care

Through the ability to perceive and communicate, the individual enriches its knowledge referential, express feelings and thoughts, clarifies, interacts, and knows what the other persons think and feel.

Since communication is a working tool for nursing, it must be effectively applied in the care provided, regardless of the hospitalization place and the complexity level of health/disease presented by the patient. It’s through communication that trust bonds are created both with patients and their relatives; they enable an early contact and ensure a continued process, investing time to be with them and don’t restricting the professionals to the physical aspects of care.

All studies identified that communication constitutes a cornerstone of palliative care and that its proper use is a proven effective therapeutic measure for patients with no possibility of cure. Nevertheless, 3 papers analyzed articles stressed that communicating in palliative care is a challenge, mainly because the interpersonal relationship developed with the terminally ill patient is influenced by the meaning that both the patient and the health professional attribute to the process. In addition, there’re numerous changes in the patient’s life resulting from the disease and treatment, which, certainly, act on the approaches adopted by them.

Often, the closeness to death leads one to deny patients the right to choose between treatment options and to join groups of palliative care which do provide an improved quality of life.

Given this, one notices the need for training and acceptance on the part of professionals with regard to the establishment of an effective communication, which, in fact, provide the patient with the maximum comfort and dignity and contributes to a better quality of her/his remaining lifetime.

Communication allows a genuine caring for the patient, because it allows her/him to express her/his needs in search of solutions, with an emphasis on her/his individuality, promoting an interpersonal relationship as a proposal to minimize the depersonalization process experienced by the hospitalized human being through an integral care.
In this context, palliative care focuses on its attributes to lead the health care team, patients, and relatives to get closer at levels which go beyond the clinical dimension. The perspective of experts in palliative care is enhanced through the patients and relatives’ experience, creating the conditions for health professionals to resort to the principles of life sacredness and address the principles of quality of life.

The quality of care at the end of life identified by the physicians and nursing team may not be the same as that identified by the patients themselves. These contacts constitute unique ways of learning, in which patients and their relatives benefit from the experience enabled by the simultaneous perspectives of various professional categories. On the other hand, professionals are exposed to a unique experience: moments of serene farewell, which are rarely observed in intensive care units and emergency wards. Thus, they develop a vision which goes beyond the diagnosis and therapeutics, processes which, in palliative care, are provided by communication.  

Therefore, although only 3 papers have pointed out information as a challenge both in the relationship between the team members and in the relationship between the practitioner, patient, and family, the need for professional training becomes evident, as well as acceptance with regard to the terminal illness for establishing an effective communication, taking into account the importance it has to care towards the dying process.

♦ The influence of communication on the quality of care

Eight studies addressing the nurse’s need to use various forms of communication and employing both the verbal and non-verbal communication, in order to enable a more accurate recognition of the patient’s feelings, her/his doubts and difficulties in verbalization, to provide an integral and humanized care. It’ll enable the patient and her/his family to experience feelings of satisfaction and safety with regard to the care provided, and the more comfort and safety the family receives, the more positive the experience is.

One believes that, to provide a good quality care, there’s a need, during nursing care, for gaining the patient’s trust and establishing meaningful ties, something which is possible by designing an effective communication. Corroborating this way of thinking, in a study carried out with female nurses from a reference hospital in cancer treatment in Fortaleza, it was found out that the provision of an integral and humanized care is possible only when the nurse uses various means of communication to perceive, understand, and employ verbal and nonverbal communication.

Communication in nursing is a process under constant construction which never repeats the same way. The conditions are always different, varying with regard to humor, layout, location, time, space, and way how the patient’s feelings are perceived.

A study developed with the aim of focusing on communication at the end of life pointed out that, when effectively provided, information results in a positive health care experience both for the patient and her/his family.

Having this in mind, one can realize the vital role of communication for establishing a bond relationship with the patient and the need, as health professionals, for continued improvement in this difficult task. It’s worth remembering that communication is influenced by the individual’s culture, her/his own social world and personality.

It was also identified in the analyzed articles that the communication between members of the interdisciplinary health team has become an indispensable tool for integrated work and a good quality care, because it favors the use of techniques related to personal relationships. Specifically with regard to the patient diagnosed with an incurable disease, the act of communicating becomes procedural, trying to avoid fantasies and fears about death. Team members should restrict dialogues related to death to themselves, so that the group embraces the theme and the blame doesn’t rely on one only team’s member, in order to promote an experience which provides understanding and growth for all professionals, besides implementing a good quality care.

Regarding the physician-terminally ill patient relationship, in 2 papers a fact deserving mention was found: it’s usual for the physician to think that her/his task ended when nothing else can be done for curing the patient. Frustration is due to this way of thinking, because the physician feels that her/his presence along with the patient is worthless and embarrassing. As a consequence, the physician-patient dialogue ceases precisely at the moment when the latter needs more support and solidarity. Moreover, it’s usual that the physician chooses not to tell the patient the truth (or the whole truth) related to her/his true health status, as...
she/he understands that knowing the truth can become responsible by emotional and/or psychological mismatches. In fact, by this protection act, the patient is deprived of her/his autonomy and her/his right to know the truth is denied.7

On the other hand, one emphasize that communication shouldn’t be terminated in the face of the death process, but strengthened, in order to allow the patient to be aware of her/his general status. Furthermore, it’s in the terminal phase that many patients feel even more desire to speak, to be heard, and getting answers. When this doesn’t occur, their dignity is stolen. Unlike, when information is shared with patients and their relatives, it promotes the expansion of her/his personality, and a new kind of learning is added to it: the positive aspect that this experience contains. Nevertheless, it’s worth pointing out that the patient her/himself is the one who should choose between the possibility of prolonging life through therapeutic interventions or not, and, for this, the need to be informed about her/his actual health status becomes clear, as it’ll provide the care with quality.4

For these reasons, a good quality care requires professionals with effective communication skills, i.e. the team should be responsible for the patient, in order to establish a bond which allows an understanding on the individual as a whole, to provide her/him with relief and comfort and contribute to a dying process with dignity.

Knowing the barriers in the communication process with the terminally ill patient

In this category it was possible to identify, in 3 studies analyzed, the reference to the existence of many barriers and the lack of skills and knowledge of nursing professionals with regard to communication with patients without cure possibilities. Communication was pointed out by nurses as an important therapeutic resource, but not that easy to be implemented, due to the difficulties they find for establishing an effective communication, alleging lack of preparation in this regard.8

Many professionals are unaware of therapeutic communication techniques, thus, they generally avoid verbal contact with the patient who experiences the dying process, moving away because they don’t know how to deal with the death situation. This behavior ends up not appreciating the fact of being together, the look, and putting oneself in another one’s shoes, something which certainly influences the behavior and values of the patient with a malignant disease.15 This fact becomes even more worrying when it comes to the nurse and her/his team’s role to directly interact with the patient and her/his relatives during hospital stay.3,14

In a study17 carried out in order to investigate the training of nursing undergraduate students to face the reality of death, it was found out that the undergraduate students themselves refer not receiving adequate preparation to experience the death process of their future clients, due to few opportunities to discuss this theme during the undergraduate course, something which reveals itself as a barrier to the development of an effective communication and a humanized care.

Regardless of the way how we communicate, there’re some elements which are indispensable for a good communication – such as patience, transparency, safety, and good teaching skills. Moreover, some strategies may be used to develop a good communication – e.g. promoting empathy, creating an environment with interaction, repeating information whenever needed, knowing how to listen, using an appropriate voice tone, being honest and transparent, provide time, keeping a consistent discourse, using simple language, keeping physical contact (touch), and showing good facial expressions, adequate physical appearance, and good body posture.32

Taking these findings into account, it becomes clear that the health professionals still avoid significant discussions related to the topic, even having to experience death at any moment in their professional practice. The occurrence of this fact is due to the beginning of everything, that is, the undergraduate training of these professionals, which, still today, is only directed to life promotion, recovery, and preservation. Therefore, it’s hard for them to understand death as a part of the life cycle. In spite of everything, they should know that this understanding is a key step for the implementation of palliative care.21

A comunicação frente ao processo de terminalidade...

Through this survey, one realized that communication is presented as something inherent to the palliative care practice. The studies analyzed highlight the importance of establishing an effective communication between the team, patient, and family, but they don’t present strategies which can be adopted in our routine in order to improve this communication and enable the humanization of the care provided.
simple fact of knowing that communication is important isn’t enough to ensure it’s used in a proper manner, since what matters isn’t what is transmitted, but the way how it’s transmitted.

The approach to complexity in this area of nursing work requires commitment from the health care team, through interdisciplinary work, in order to meet, to the possible extent, the client and her/his family’s needs in the face of uncertainties, diversities, and unpredictabilities which mark the complex reality and the client’s clinical instability as death closes in.

Given this scenario, there’s a need that professionals are trained and skilled to care for this population, in order to minimize the suffering caused by terminal illness and maintain these patient’s autonomy and human rights.

This finding suggests the need for nurses to think through their scientific production with a better dialogue between academy and assistance, not only disseminating the objectives and outcomes of their actions, but detailing the actions implemented along with the team, the family, and the terminally ill patient. Thus, one reaffirms the nurse’s need for working along with this patient, in order to provide her/him with a humanized care, taking into account her/his individual characteristics.

Finally, one stresses the need for, already during the undergraduate course, introducing to the professional the communicative process as a nursing work tool, aiming to promote the establishment of true and meaningful relationships between students, nurses, patients, and relatives.

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