FAMILY PARTICIPATION IN PALLIATIVE CARE: A SYSTEMATIC REVIEW
PARTICIPAÇÃO FAMILIAR NOS CUIDADOS PALIATIVOS: REVISÃO SISTEMÁTICA
PARTICIPACIÓN FAMILIAR EN LOS CUIDADOS PALIATIVOS: REVISIÓN SISTEMÁTICA

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ABSTRACT

Objective: To identify the best available evidence about family participation in the palliative process, as well as the communication strategies used by the family and the health team in the end-of-life decision-making process. Methods: A systematic literature review, searching the PubMed and Lilacs databases, with the following keywords: "Palliative Care" AND "Decision Making" AND "Family". This research followed the guidelines for systematic review and meta-analysis (PRISMA). After the selection procedure, the sample retrieved 14 scientific articles. Results: Four thematic categories of the selected studies’ descriptive analysis were apprehended, namely: "The facilitator as a communication agent", "Media tools", "Meetings with the specialized team" and "Training and assessment of communication between team and family", which evidenced the construction of an intervention: Team-family communication to build shared palliative care. Conclusion: Palliative care recommends family participation in the decision-making process, so it is necessary to carry out multidisciplinary and interdisciplinary teamwork. The communication strategies adopted must be clear to family members, seek shared care and minimize the suffering of families.

Descriptors: Palliative Care; Decision Making; Bioethics; Patient Care Team; Family.

RESUMO

Objetivo: Identificar as melhores evidências disponíveis sobre a participação familiar no processo de paliatividade, bem como as estratégias de comunicação utilizadas pela família e equipe de saúde no processo decisório de fim de vida. Métodos: Revisão sistemática da literatura, com busca nas bases de dados PubMed e Lilacs, com as seguintes palavras-chave: "Palliative Care" AND "Decision Making" AND "Family". Essa pesquisa seguiu as diretrizes para revisão sistemática e meta-análise (PRISMA). Após procedimento de seleção, a amostra compreendeu 14 artigos científicos. Resultados: Foram apreendidas quatro categorias temáticas da análise descritiva dos estudos selecionados, a saber: "O facilitador como agente da comunicação", "Herramientas de media", "Reuniones com equipe especializada" e "Treinamentos e avaliação da comunicação entre equipe e família", que evidenciaram a construção de uma intervenção: Comunicação equipe-família para construção de um cuidado paliativo compartilhado. Conclusão: O cuidado paliativo preconiza a participação familiar no processo de tomada de decisão, para tanto é preciso realizar um trabalho em equipe multiprofissional e interdisciplinar. As estratégias de comunicação adotadas devem ser compreensíveis aos familiares, buscar o compartilhamento do cuidado e minimizar o sofrimento das famílias.

Descritores: Cuidados Paliativos; Tomada de Decisão; Bioética; Equipe de Assistência ao Paciente; Família.

RESUMEN

Objetivo: Identificar la mejor evidencia disponible sobre la participación familiar en el proceso paliativo, así como las estrategias de comunicación utilizadas por la familia y el equipo de salud en el proceso de toma de decisiones al final de la vida. Métodos: Revisión sistemática de la literatura, con búsqueda en las bases de datos PubMed y Lilacs, utilizando las siguientes palabras clave: "Palliative Care" AND "Decision Making" AND "Family". Esta investigación siguió las pautas de revisión sistemática y metaanálisis (PRISMA). Tras un procedimiento de selección, la muestra estuvo compuesta por 14 artículos científicos. Resultados: Se aprehendieron cuatro categorías temáticas del análisis descriptivo de los estudios seleccionados, a saber: "El facilitador como agente de comunicación", "Herramientas mediáticas", "Encuentros con equipo especializado" y "Capacitación y evaluación de la comunicación entre equipo y familia", que evidenció la construcción de una intervención: Comunicación equipo-familia para construir cuidados paliativos compartidos. Conclusión: Los cuidados paliativos recomiendan la participación familiar en el proceso de toma de decisiones, por lo que es necesario realizar un trabajo en equipo multidisciplinario e interdisciplinario. Las estrategias de comunicación que se adopten deben ser comprensibles para los familiares, buscar compartir los cuidados y minimizar el sufrimiento de las familias.

Descritores: Cuidados Paliativos; Toma de Decisión; Bioética; Equipo de Atención al Paciente; Familia.

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INTRODUCTION

Palliative care consists of assistance provided by a multidisciplinary team to improve the quality of life of patients and their families due to a disease that threatens the continuity of life, by the early identification of suffering relief measures, handling of pain, also biopsychosocial spiritual symptoms. From the resolution of the Ministry of Health no. 41/2018, this practice has become part of care within the scope of the Unified Health System (SUS) (Sistema Único de Saúde), which must be offered at all levels of care, being either basic, at home, outpatient, urgent and emergency or hospital(1).

Palliative care started in Brazil in the years 1980s and there was a significant growth since the year 2000 with the creation and consolidation of pioneering services. Currently, there are more than 40 health services startups specialized in palliative care across the country, which can still be considered incipient, given the extensive territorial space in Brazil and the growing demand for palliative care(2).

Health professionals and family are essential pillars in the care of palliative patients(3). The presence of the multiprofessional team in palliative care brings a positive advance to the support, as it can influence the understanding and acceptance of the disease, in the planning of patient care, when hospitalized and at home, strengthening family bonds and consequently reducing anxiety and suffering of all the people involved(4).

In this respect, the family is considered the main source of emotional and social support for the palliative patient, as it plays an important role in the decision making and desires of the loved one. However, there are two models concerning the issues involving terminally ill care: the paternalistic model - in which the doctor informs his/her choice to the patient - and the shared model - when decisions are the result of dialogue among doctor, patient and family. Regardless of the decision-making model, a collaborative family attitude benefits patient care and also includes them as an item of care by professionals, since the one who is at the bedside also needs to be cared for, as being in suffering when assuming this new and complex role of caregiver(5,6).

When the patient is unable to decide for himself/herself, a legal person must be named, usually a family member. Many authors question whether the family’s point of view should prevail over the will and opinion of the sick person since their autonomy must be respected. An example of this is when the family wants to save the suffering and reduce the worry, requesting that information about the real condition of health is not revealed to their loved one(7,8).

Furthermore, professionals, specifically doctors, struggle to inform end-of-life situations to the family and the patient. This, possibly, is related to emotional overload when it comes to dealing with the possibility of the patient’s death. Moreover, professional unpreparedness is because themes such as finitude and communication of bad news are not addressed frequently and/or deeply in medical schools(9).

There is no room for doubt in which if the training is not satisfactory, there are considerable impacts on the communication process among professionals and family members/patients. There is still, by the professionals, a lack of knowledge and non-acceptance of the term palliative care, assuming that it would be abandoning the patient, both by the medical team and the caregiver(9).

Thus, when analyzing the complexity of palliative care and the importance of family participation in decision-making in the final stages of life, it is believed that knowing and compiling scientific evidence in the light of palliative communication strategies will contribute to society, professionals and academia when proposing to bring an update on the types dimension and communication strategies between and for the health team and family, also addressing family rights.

So, considering the importance of discussing and understanding the palliative care theme, the following question came up: What scientific evidence is available on strategies for communication between the family and the health team in the decision-making process at the end of life? To search for the answer to this question, a systematic literature review was carried out based on the model Population, intervention, comparison, outcome (PICO), whose objective was to identify the best available evidence on family participation in the palliative process, also the communication strategies used by the family and the health team in the end-of-life decision-making process.

METHODS

This review followed the guidelines for systematic reviews and meta-analyses (PRISMA)(10), in which it comes to the phases of choosing the data sources, choosing the descriptors, searching for articles, analyzing the titles and abstracts, reading fully the texts, adopting inclusion and exclusion criteria, data.
Family participation in palliative care

From September of 2019 to December 2019, a search was carried out, without language restriction, in the PubMed and Lilacs databases. For that, the descriptors MESH terms were used: Palliative Care AND Decision Making AND Family.

The articles identified by the initial search strategy were independently evaluated by two authors, according to: (1) population (patients in palliative care, their families and health professionals); (2) intervention (use of different communication strategies between health professionals and family members); (3) comparison (traditional communication with shared medical meetings); (4) outcome (effective family participation).

The inclusion criteria of the articles were: to be fully available online, to belong to the descriptive research type, randomized clinical trial, case series, cohorts or experimental clinical studies that showed results of primary studies about palliative care, decision making and the family’s role.

In the initial search, 48 possible studies were retrieved, with 44 publications in the PubMed database and 4 publications in the Lilacs database. In this initial search, the articles were separated by two reviewers, who independently selected the studies by titles and abstracts, to establish the relevance. Thus, 33 studies were excluded which were not in line with the methodology and were not fully available. Then, the document was entirely read to analyze the publications that answered the review objective in this process of the 15 publications included, one was removed because it did not meet the research theme, resulting in 14 selected studies.

Figure 1 shows the flowchart of the process applied for the selection of the articles included in the systematic review.

![Flowchart](image)

**Figure 1:** Flowchart for searching and selecting scientific texts.
Source: Data collection, 2019.

Thus, the analysis of publications was performed initially from abstracts reading, with a subsequent reading of the entire text, considering the methodology for characterizing the publications. In this process of in-depth analysis and registration of the sample information, a systematic instrument was used, which consisted of: Author and
Year, Objective, Type of study, Participants, Type of intervention and Main results. This stage of data extraction was developed by a single researcher in a simple-blind way.

The findings of the primary studies were compiled and categorized through a comparative analysis among the results. Thus, from the descriptive analysis of the selected studies, four thematic categories were apprehended, which were repeated, about the strategies for effective communication between the health team and the family in the palliative process, namely: “The facilitator as a communication agent”, “Media tools”, “Meetings with the specialized team” and “Training and assessment of communication between team and family”. The discussion of these resources showed an intervention called: Team-family communication for the construction of shared palliative care, which along with the discussion of the categories supports the comparison of findings with the literature about the subject.

RESULTS

From the fourteen publications, it is emphasized that eight (58%) were randomized studies, one (7%) was an experimental study, one (7%) was a qualitative study, one (7%) was a retrospective descriptive study, one (7%) was a cohort and two (14%) were observational. As for the year of publication, it was found that two articles (14%) were published in 2018, seven (50%) in 2017, two (14%) in 2016, one (7%) in 2013, one (7%) in 2008 and one (7%) in 1995.

A total of 10,375 people participated in these primary studies, including patients, family members and health professionals. And it stands out that 08 studies (58%) were carried out in the United States; 03 (21%) in Australia, 01 (7%) in Japan; 01 (7%) in Uruguay and 01 (7%) in Canada.

Regarding the findings in the included primary studies, chart 1 shows the characteristics and parameters evaluated in each of them.

DISCUSSION

The identified categories are introduced from the descriptive analysis of the results of the primary studies and these categories are compared with the current scientific literature on the subject.

The facilitator as a communication agent

The results categorized in this section were those that showed the use of strategies to improve team-family communication. The presence of the facilitator (for example: clinical nurses, oncology nurses, social workers and other professionals through training) helped to mediate conflicts, understand medical language and assist in decision-making at the end of life, also aiming to reduce anxiety and depression of family members

However, it is noteworthy that in an Australian study, the communication did not result in an improvement in the well-being of the family and in the case of patients with low attendance to care planning meetings. The authors stressed that the success of the meetings depends on the communication skills of the facilitator and the involvement of patients and/or family members; sometimes patients and family members do not want to get involved, that is why meetings facilitated by health professionals outside the treatment team cannot be ideal in these cases

The use of communication facilitators to reduce the family’s depressive symptoms was also evaluated. As a result, it was identified that there was no significant short-term difference in depressive symptoms among family members who received information through facilitators. In this sense, such studies do not recommend the routine discussion of palliative care with the family, since there was a development of post-traumatic stress in the family members when receiving more frank and clear information about the end of life of their loved one.

On the other hand, for other families, the participation in decision-making in palliative care with a facilitating professional, provided family members to get information to support the discussion with the clinical team and assist in better decision-making regarding their loved one. This aspect is relevant because sometimes the family does not know which is the best therapeutic decision to be made, and by not knowing they do not join in the palliative process effectively.

Another important aspect regarding the character of the facilitator is that he/she can work as an agent to get more family information about the patient’s preferences. However, a survey showed that only 47% of doctors knew that their patients preferred not to receive cardiopulmonary resuscitation. That is, although the facilitators identify the preferences of the patient and their families, sometimes the information is not provided to the health team. This is something that needs to be considered in palliative care services, as communication among team members is as greatly relevant as communication between professionals and families/patients.
Family participation in palliative care

**Chart 1** – Distribution of articles that make up the study sample according to authors, year, objective, type of study, participants, type of intervention and main results.

<table>
<thead>
<tr>
<th>Author / Year</th>
<th>Objective</th>
<th>Type of study</th>
<th>Participants (N)</th>
<th>Type of intervention</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Johnson et al. (2018)</td>
<td>To evaluate an advanced care planning (ACP) intervention.</td>
<td>Randomized study</td>
<td>208 patient-family dyads.</td>
<td>The ACP was based on the Respecting Patient Choices model.</td>
<td>There was no difference in care and participation of the family, despite noticing an improvement in the understanding of medical information.</td>
</tr>
<tr>
<td>Nishioka et al. (2018)</td>
<td>To clarify the appropriate communication style for doctors.</td>
<td>Experimental psychological study</td>
<td>251 doctors and nurses</td>
<td>Scripted videos used. In the videos, the doctor described treatment options, using an autonomous or paternalistic style.</td>
<td>Most participants preferred the autonomous style.</td>
</tr>
<tr>
<td>Agar et al. (2017)</td>
<td>To analyze the effects of comparing the performance of nurses in planning palliative care with the usual care received at the end of life in a hospice.</td>
<td>Randomized controlled study</td>
<td>286 people with advanced dementia, their families, and professional caregivers.</td>
<td>Palliative Care planning coordinators held conferences with family members and trained personnel in person-centered palliative care.</td>
<td>A systematic approach to improve a palliative approach and the upgrade of skills (of caregivers) caused improvements in care.</td>
</tr>
<tr>
<td>Epstein et al. (2017)</td>
<td>To determine whether a combined intervention involving oncologists, advanced cancer patients and caregivers would encourage patient-centered communication and estimate the effects of the intervention on shared care.</td>
<td>Randomized clinical trial</td>
<td>38 oncologists and 265 patients, 194 caregivers.</td>
<td>Oncologists got individualized communication training using standardized instructors, while patients got question lists and individualized communication training.</td>
<td>In fully adjusted models, the intervention resulted in clinical and statistically significant improvements at the final line of primary physician-patient communication.</td>
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<td>Hannon et al. (2017)</td>
<td>To determine, from the patient's perspective, the experience of receiving early palliative care.</td>
<td>Qualitative</td>
<td>40 patients, including major caregiver</td>
<td>Interviews with patients and families who received specialized care.</td>
<td>Receiving early specialized palliative care has enabled holistic support for patients and caregivers, guidance in decision-making helping in the interpretation of medical information and preparation for the future.</td>
</tr>
<tr>
<td>Hanson et al. (2017)</td>
<td>Test a decision-aid intervention with treatment objectives to improve the quality of communication and palliative care for arrest home residents with advanced dementia.</td>
<td>Single Cluster-blind, randomized clinical trial</td>
<td>302 asylum residents and their families.</td>
<td>Video decision contribution plus structured discussion with healthcare providers in hospice.</td>
<td>The primary outcomes were the quality of communication, family report complying with doctors about the main objective of care and treatment consistent with preferences.</td>
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<tr>
<td>Pereira et al (2017)</td>
<td>To describe the characteristics of the children attended in a pediatric palliative care unit with Guidelines for Diretriz de Adequação do Esforço Terapêutico (DAET) (Adequacy of Therapeutic Effort - ATE) and the level of SMR (Adequacy of Therapêutic Effort - ATE) and the level of ATE) (Adequacy of Therapêutic Effort - ATE) and the level of</td>
<td>A descriptive, retrospective study</td>
<td>618 children and adolescents with health conditions subject to palliative care</td>
<td>Analysis in a database of the studied place, about the DAET achievement: meetings of a health team, interviews with families and record in the medical report.</td>
<td>A progressive increase in ATE in specific records was observed. ATE were respected in virtually all cases.</td>
</tr>
<tr>
<td>Study Authors and Year</td>
<td>Study Type</td>
<td>Sample Size</td>
<td>Intervention</td>
<td>Outcome Measures</td>
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<td>Walczak et al. (2017)</td>
<td>Randomized controlled parallel-group study</td>
<td>110 patients and caregivers (named by patients)</td>
<td>The communication support program included a guided examination of a list of questions, communication challenges, patients’ values and concerns, and the value of early discussion of end-of-life care.</td>
<td>Facilitators of the communication support program provided significantly more tips for discussion of prognosis, end-of-life care, future care options and general issues not handled by the intervention during consultations with recorded oncologists.</td>
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<tr>
<td>Curtis et al. (2016)</td>
<td>Randomized study</td>
<td>168 patients (268 family members)</td>
<td>Use of facilitators for communication among doctors and family and conflict mediation.</td>
<td>There was a decrease in the family depressive symptoms in the long term, a decrease in the costs of the Intensive Care Unit (ICU) and a reduction in the hospital stay.</td>
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<td>Carson et al. (2016)</td>
<td>Multicentre randomized clinical trial</td>
<td>Intervention group: 130 patients and 184 decision-makers. Control group: 126 patients and 181 decision-makers.</td>
<td>Structured family meetings led by specialists in palliative care and handling of an information brochure (intervention) compared to the handling of an information brochure and routine family meetings carried out by ICU teams (control).</td>
<td>By 3 months, there was no significant difference in anxiety and depression symptoms between substitute decision-makers in the intervention group and the control group.</td>
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<tr>
<td>Ramos et al. (2016)</td>
<td>Observational study</td>
<td>1173 nurses</td>
<td>We examined associations between predictors evaluated by the nurse (doctor-nurse communication, doctor-family communication) and nurses’ ratings about the quality of dying of patients.</td>
<td>Medical support for family decision-making was particularly important, suggesting a potential target for interventions to improve end-of-life care.</td>
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<tr>
<td>Vogel et al. (2013)</td>
<td>A randomized controlled pilot study</td>
<td>53 women and family members invited</td>
<td>A prototype website was created to manage advanced service planning.</td>
<td>The women were satisfied with the quantity and quality of the information on the website and used it for longer. The overall use of the site was lower than expected.</td>
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<tr>
<td>Gries et al. (2008)</td>
<td>Cohort study</td>
<td>356 families</td>
<td>Questionnaire and graphics abstraction.</td>
<td>The family’s satisfaction with decision-making was associated with the extraction of life support, and the documentation of medical recommendations for extraction of life support, discussions of patients’ wishes and discussions of the families’ spiritual needs.</td>
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<tr>
<td>Connors (1995)</td>
<td>Prospective observational study</td>
<td>4,301 patients (phase I), 4,804 patients and their doctors (phase II)</td>
<td>A specifically trained nurse had several contacts with the patient, family, doctor and hospital staff to acquire preferences, improve understanding of results, facilitate advanced care planning and doctor-patient communication.</td>
<td>Phase I confirmed deficiencies in communication and frequency of aggressive treatment. In phase II, patients did not show improvement in communication consequently in the care received. To improve the experience of critically ill patients, it may be necessary a greater individual and social commitment and more proactive and robust measures.</td>
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Source: Data collection, 2019.
Use of media tools

To improve the quality of communication and the care provided to patients and their families, some studies\(^{(12,16)}\) used informative and descriptive videos as a tool. A website was also developed as a strategy to manage the planning of care and consultation of palliative care for women with ovarian cancer also available to family and/or caregivers\(^{(22)}\).

It is observed that the use of different communication strategies in palliative care is not restricted to the discussion with family members and patients who are admitted in hospitals, but also those who are being followed up on an outpatient basis in oncology clinics\(^{(12)}\) and with elderly asylum residents with dementia\(^{(16)}\).

Research\(^{(12)}\) used a video for communication and evaluated the family member’s preference concerning the communication style: autonomous or paternalistic. Most preferred the autonomous style, in which the family has the autonomy and power of mutual decision-making with the team. In contrast, some family members believed that the video with paternalistic language produced less suffering because they had little participation and information about palliative care and the patient’s progress.

It was found that websites can be developed based on a mutual decision with patients and family members, aiming to facilitate discussions about the quality of life and end of life care. However, it is necessary to expand the participation of caregivers, as research\(^{(22)}\) with family members and patients terminally ill with cancer showed that the search was small and mainly the access to the site was less than expected. Yet, patients who accessed the site were satisfied with the quality and amount of available information. Even though, it is noteworthy that in palliative care, communication with the family plays a major role in the process, and they must also be inserted in awareness activities and use different tools for the acquisition of knowledge that assist in the provision of continuous care\(^{(3)}\).

Meetings with the specialized team

In this category, studies were included in which communication with the family took place through meetings with a specialized team in palliative care, at specific times\(^{(13,15,20)}\).

Family meetings with palliative care teams were evaluated\(^{(13,15)}\), including the training of caregivers to improve care. Regarding family participation, it was observed that it provided holistic support to patients and caregivers and guidance in decision making\(^{(15)}\), however the authors refer that there is no need for formal meetings such as family conferences and suggest informal meetings with nurses for example, to deal with patient care\(^{(13)}\).

Anxiety and depression were assessed in relatives of terminally ill patients\(^{(20)}\). The authors pointed out that the routine of family meetings should be cautiously observed, as they found that in the group in which the meeting with specialists took place with the hand-out of an information booklet, the same results were found for symptoms of anxiety and depression in the family that attended meetings with physicians. However, it is reinforced that in other end-of-life contexts, such as the emergency, shared information seems to reduce the suffering of family members and patients\(^{(23)}\).

Training and assessment of communication between team and family

Despite the understanding of holding meetings or consultations with family members and caregivers, some professionals do not have the skills to carry it out or struggle using words and understanding the role of the family in decision-making\(^{(14)}\). Thus, studies\(^{(14,23)}\) were carried out to promote training focused on communication with oncologists, and with family members to help them identify issues to be solved in clinical meetings, which resulted in more effective communication.

Other studies\(^{(17,21,23)}\) assessed the quality of communication between the team and the family in a hospital environment, in which it was emphasized the importance of shared decision-making to increase the quality of life in the final stage, such as knowing the patient’s wishes. It is also emphasized that palliative care must be recorded in medical records and work must be accomplished to promote an end of life according to the wishes of the patient and family\(^{(24)}\).

Team-family communication to build shared palliative care

It is observed that, more than communicating with the family, it is necessary to use effective communication strategies, avoiding metaphorical and ambiguous language, and carry out clinical meetings with direct and effective language to bring understanding and explanation to those who will listen\(^{(20)}\). The Ministry of Health of Brazil\(^{(1)}\) emphasizes that communication must be sensitive and empathetic, for truth and honesty in all matters involving patients, family members and professionals, besides offering a support system to help the family dealing with the patient’s illness and grief.

It is verified that many of these meetings were facilitated or carried out by nurses,
However, if the professional struggle in accepting his/her finitude, he/she can inspire false hopes in the patient and his/her family. Also, nurses were formerly discouraged from showing their emotions, thus promoting cold objectivity. Currently, it is known that the emphasis on meeting all the individual’s needs includes family support and continuous communication among the parties involved.\(^{(27)}\)

So, for proper communication through the interaction among the health professional and the patient and his/her family, it is essential to train the professional to know the best communication strategies, as well as offer training to the family to help them in identifying patient needs and how to ask questions relevant to care and prognosis.

Besides the professional’s training to develop better communication with family members and patients, the importance of studying palliative care since undergraduate school is highlighted, with theoretical subjects in medical and nursing schools so that the student learns and develops this communication from the beginning of their training. Assistance to patients in palliative care since graduation improve the development of practice without theory due to the lack of discipline in some school curriculum, however, by experience, empathy can be acquired, to be at the other’s place, and understanding that the palliative care is done in an interprofessional way.\(^{(28)}\)

The treatment of the disease and the control of signs and symptoms are understood as easy, or at least they can be learned and accessed. However, checking with and talking to terminally ill patients is more complex, as this is an area of health training that is deficient for doctors and nurses and is still necessary for everyone. Dealing with the death-dying process is difficult for people, as it raises doubts about their finitude, which in many cases results in “spiritual pain”. This contributes to the fact that grief is neglected in palliative care. In this sense, the key point in the patient’s death-dying process is communication and compassion.\(^{(29)}\)

During communication, the family plays a leading role in care, since they are the first caregivers and will provide central information about the patient during palliative care that will culminate in comprehensive care, that is, aiming at quality of life in the physical, psychological, social and spiritual context.\(^{(6)}\) Added to the importance of family participation in the context of comprehensive care, preserving human dignity, the uniqueness of each individual and their autonomy, whether expressed by a patient or family member, is an ethical issue.\(^{(30)}\)

Communicating with seriously ill patients and family members is a therapeutic art and should be learned and practiced in a safe environment, such as a clinical skills laboratory with students and professionals. For communication and effective listening, the professional must: talk privately, allow the patient and family enough time to reflect after a question, do not fill the “space” in the communication with the conversation, avoid “ready” responses, ask questions and evaluate understanding - your own and the patient/family’s - restating, summarizing and reviewing.\(^{(31)}\)

**CONCLUSION**

Most of the articles showed the adoption of strategies for communication between the health team and the family when confronted with palliative care decisions offered to the patient. They indicate that the strategies used for communication, whether through meetings with a specialized team, using media or mediated by a facilitator, must be comprehensible to the family and not trigger greater suffering than that inherent to the health-disease process.

Palliative care is care that calls for multi-professional and interdisciplinary teamwork to meet the needs of the patient and family. On the other hand, not all professionals are trained to carry out effective and humanized communication with the patient’s family. By the studies analyzed, there is a deficiency in the provision of permanent education to workers. Besides the importance of approaching the theme of palliative care in higher education, focusing, among other points, on the adoption of team-family communication strategies, according to the particularity of each case.

Families have different experiences with the death-dying process, but in general, dealing with palliative care causes a lot of suffering and tensions, being necessary to evaluate the need for the attendance of the family meetings not to exclude the family from the process, but also not to increase the family suffering.

It is observed that discussions about ways to improve communication at the end of life between professionals and family, seems to be still not very expressive in our country since there was no Brazilian study among those analyzed. This has consequences. Clinical decisions end up being made by the medical team and/or the multidisciplinary team without the knowledge of the family and patient, which can lead to conflicts and even lawsuits. The result of the systematic review shows that we still live far from a health model in which empathetic and shared
communication with those involved in the health-disease process is the central axis of decision-making.

As a limitation of the study, the difficulty in finding research that aims to investigate professional communication is mentioned. Also, the fact that reviews input was limited in this selection of studies. In this sense, future investigations aimed at communication in palliative care and the death-dying process are necessary to spread the relevance of the holistic approach in which the professional, besides offering support to the patient and family, shares and discusses the care offered.

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