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CONSPIRACY OF SILENCE IN PALLIATIVE CARE: LITERATURE REVIEW

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ABSTRACT

Introduction: The diagnosis of advanced diseases triggers complex emotional reactions in patients and family members, often resulting in hesitation to discuss with the health professional about the process of imminent death the junction of feelings of the patient and family, known as the conspiracy of silence. Objective: To understand the impact of the conspiracy of silence on patients in palliative care. Methodology: The research was carried

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out through a bibliographic search in the Pubmed and Virtual Health Library databases, using the health descriptors: "Decision making"; "Palliative Care"; "Health Communication" in the last five years and aims to understand the impact of the conspiracy of silence for patients in palliative care. Results: The lack of transparency hinders open communication, which is essential for the patient to express their desires and fears, and for the family to offer the necessary support. Conclusion: The need for professional communication is evident as a tool to assist the expression of patients and their families.

Keywords: Decision Making. Palliative care. Health Communication.

INTRODUCTION

Palliative care arose due to the need for specialized care for people with serious, progressive, and chronic diseases. They are patient- and family-centered during various stages of illness, including death and grief (Fernandes et al., 2018). The diagnosis of an advanced, incurable, and progressive disease significantly affects both patients and their families, often triggering emotional reactions such as sadness, anxiety, depression, guilt, anger, impotence, uncertainty, and fear (Scarton *et al*., 2018; Wang *et al*., 2021). When confronted with this reality, both the patient and his family are forced to reconnect and normalize as ways of attributing a new meaning to this life event, living in a flow that usually leads them to confront human uncertainty, implying an incessant capacity for adaptation (Sansom *et al*. 2021).

Silence often appears in the initial phase of palliative care, being a very common social phenomenon that involves the patient, the family/caregiver, and the health team (Ibañez-Masero *et al*., 2019). Although death is inherent to the human condition, patients and family members demonstrate communication difficulties, often resorting to the conspiracy of silence, a strategy to avoid discussing the patient's health condition, prognosis, and finitude, fearing the repercussions that knowledge of this information may cause (Nagelschmidt *et al*., 2021; Alfaya-Góngora *et al.,* 2021). The conspiracy of silence in palliative care is a complex phenomenon that involves avoidance or reluctance to openly discuss issues related to impending death, suffering, and end-of-life care. This absence of frank communication can have significant implications for terminally ill patients, as well as their family members and caregivers, leading to a decrease in quality of life, increased emotional distress, and, in some cases, poor treatment decisions (Sutar *et al*., 2019).

The conspiracy of silence is a prevalent reality in many palliative care settings, both in hospital and home settings. Many patients and family members wish to openly discuss issues related to death and the end of life, however, they face significant barriers to initiating such conversations with health professionals (Gikaara *et al*., 2020). Unpleasant news is often denied when the patient is vulnerable, especially older adults, adolescents, and children. To protect the patient, the family omits information and avoids talking about the disease, believing that the patient will suffer, which may contribute to his death (Lemus-Riscanevo *et al.*, 2019). The lack of open and honest communication about issues related to death and suffering can have a significant impact on the quality of life of patients and their families. In addition, they can negatively influence treatment decisions, leading to invasive and unnecessary medical interventions (Ferreira *et al*., 2022).

Such care is based on a flow of interactional communication between the triad: patient, family members and health professionals. Clear, open, and coherent communication that serves to inform the patient about their diagnosis and prognosis is essential, allowing the patient and family members to plan end-of-life care in advance together with the medical team (Von Blanckenburg *et al.,* 2022).

Epidemiological data demonstrate that although 70% of terminally ill patients and their families wished to discuss death, only 17% actually had these conversations with their doctors. This gap in communication can result in a range of adverse consequences, including increased emotional distress, anxiety, and social isolation for both patients and their loved ones (Costa *et al.,* 2019). The prevalence of this phenomenon in palliative care is a cause for concern, and epidemiological studies have sought to elucidate its extent. In the Brazilian context, although specific data are limited, there is evidence to suggest the significant existence of the conspiracy of silence, in which a trend towards underuse of palliative care in Brazil was identified, indicating possible gaps in communication and appropriate access to this type of care (Moreira *et al*., 2019).

Healthcare professionals also play a crucial role in patient care, although many are still reluctant to openly address end-of-life issues, for fear of causing distress to patients and their families, or for lack of adequate training in communication about death, more than 60% of professionals reported avoiding discussing gloomy prognoses with terminally ill patients (Machado *et al*., 2019).

To overcome the conspiracy of silence in palliative care, it is crucial to take a multi-pronged approach. The conspiracy of silence in palliative care represents a significant challenge that can compromise the quality of care and the end-of-life experience of patients and their families. Given this reality, the relevance of this project is justified, given the need to investigate and understand how specific interventions can help mitigate this phenomenon, promoting more open and compassionate communication between health professionals, patients, and family members.

By addressing this issue, the present study aims to understand the impact of the conspiracy of silence on patients in palliative care. To this end, it is questioned how the literature refers to the main strategies of the patient- and family-centered approach to effectively deal with the conspiracy of silence in palliative care?

METHODOLOGY

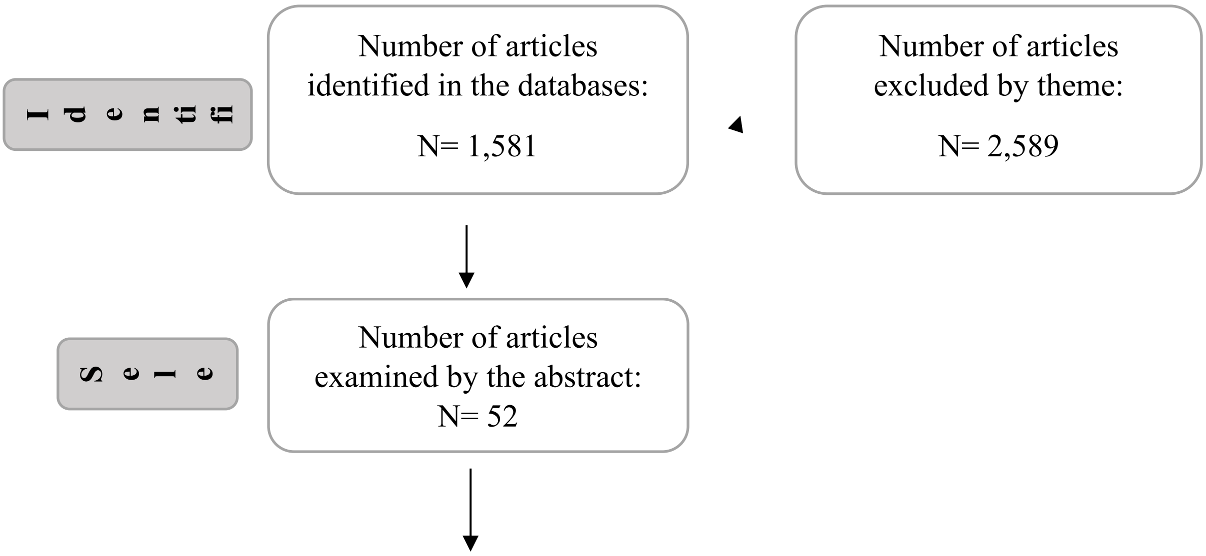
This is a bibliographic research, in which a search for references was carried out in the Pubmed and Virtual Health Library (VHL) databases, using the following health descriptors in Portuguese: "Decision making"; "Palliative Care"; "Communication in health", and in the English language: "Decision-making"; "Palliative Care"; "Health communication", using the Boolean operator "and" in the search. The search period in the last 5 years, from 2020 to 2024, will be determined.

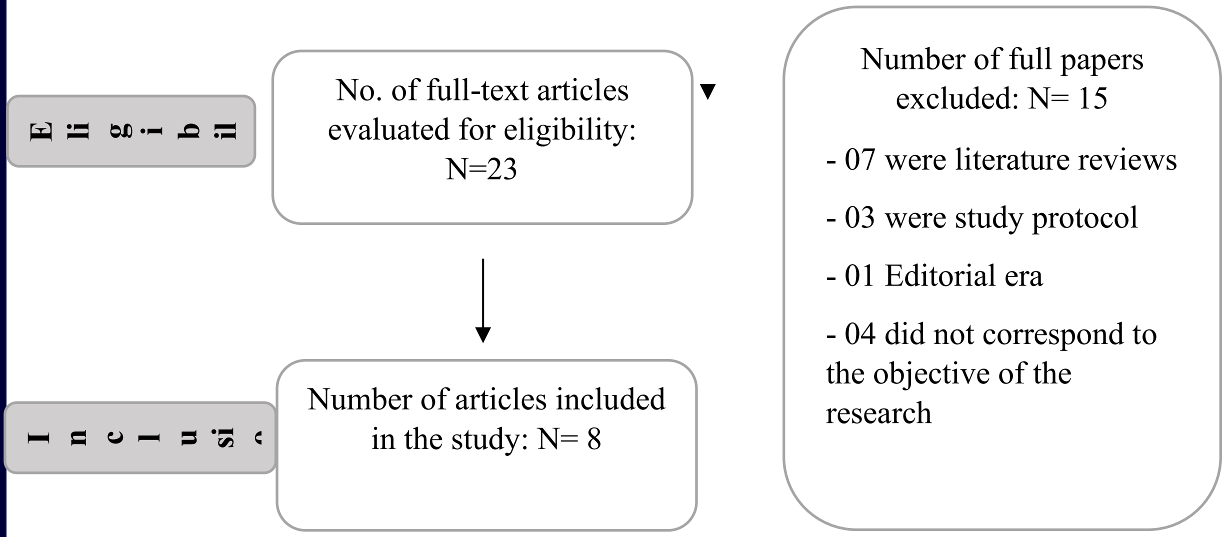
For the selection of studies, the selection criteria were based on the analyses and evaluations of the researchers, in order to identify the most appropriate studies for the research, which will use the following inclusion criteria: original articles available in full in Portuguese, English or Spanish, within the period determined in the search. Literature review articles, theses and dissertations, and articles from Ministry of Health manuals were excluded.

The data were collected through studies that correspond to the objectives of the research, with the selection of categories related to the theme in question. This approach will respect the previously established inclusion and exclusion criteria. Initially, the articles will be chosen based on the research theme, followed by the analysis of the abstracts and subsequent complete reading. After applying the selection criteria, the articles were submitted to a content analysis to identify similarities and categorize them.

The search in the databases with the keywords identified 1,581 records. After removing duplicates, and specifying the search for the last five years, 52 titles and abstracts were found. Finally, 23 articles with full texts that addressed the proposed theme were selected. After the analysis carried out by the researchers, eight studies relevant to the review were selected, which were within the proposed theme, respecting the established inclusion and exclusion criteria. The article selection process can be seen in figure 1:

Figure 1 – Flowchart for the selection of articles:





Source: Researchers' data, 2024.

As this is a literature review, there was no need to submit the research to the ethics committee.

RESULTS

A total of 52 studies were found that addressed the proposed theme. After the full reading of the articles carried out by the researchers, 8 studies relevant to the review were selected, which were within the proposed theme, respecting the established inclusion and exclusion criteria. These are present in table 1.

Table 1 – Characterization of the selected articles, published between 2020 and 2024. Maringá, 2024.

ID	Goal	Main results
01 (He *et al*., 2021)	To explore the association between early informed diagnosis and survival time in breast cancer patients in China.	Patients who were aware of their diagnosis had higher 3- and 5-year survival rates compared to those who were unaware.
02 (Avalew *et al*., 2023)	Explore the cultural preferences of Ethiopian patients regarding the reception of bad news in the context of palliative care.	Patients prefer to receive bad news in the presence of family members, however, their needs are not always met. The delivery of bad news must consider patients' cultural preferences, values, and religious beliefs to better meet their expectations in palliative care.
03 (Chang *et al*., 2021)	Assess knowledge and attitudes about key end-of-life issues and the principles of a good death among clinicians in clinical settings.	The results indicate the need for a more structured and comprehensive training, resulting in a greater awareness of the communication of bad news and other practices related to palliative care in curricula and in the continuing education of physicians.
04 (Ferreira *et al*., 2024)	To investigate and explore the strategies used by health professionals to prevent and intervene in the conspiracy of silence in the context of palliative oncology care.	Improving training and communication practices is essential to better address the conspiracy of silence and to ensure that patients and their families receive the necessary information in a clear and empathetic manner.
05 (Alsirafy *et al*., 2022)	To explore whether the decision not to inform patients about their cancer diagnosis is associated with lower levels of anxiety and depression and a better quality of life	There were no significant differences between patients who knew and those who did not know about their cancer diagnosis regarding levels of anxiety, depression, and quality of life.
06 (Shah *et al*., 2023)	To assess patients' perceptions and preferences regarding bad news in the healthcare environment in Pakistan.	Most patients prefer to be informed and want family to be communicated first, and that preferences for disclosure vary based on factors such as age, education, and income.
07 (García-Navarro *et al*., 2023)	Identify the needs of patients and their families during the end-of-life process, in order to ensure that they feel effectively accompanied and supported during this period.	During the end of life, both patients and their families have significant common needs such as communication and presence, with the conspiracy of silence identified as a major factor that generates distress for both.
08 (Carmona-Bayonas *et al*., 2023)	To analyze the prevalence, explanatory factors, and consequences of inaccurate prognostic awareness in patients with advanced cancer.	74% of patients with advanced cancer had inaccurate prognostic awareness, often due to vague communication about prognosis that did not mention death. While a realistic understanding of the prognosis was related to an increase in anxiety, depression, and a reduction in quality of life.

Source: Researchers' data, 2024.

For a comprehensive understanding of the topic at hand, the literature review has been organized into categories that reflect the main areas of debate and research in the existing literature. These categories allow a coherent structuring of concepts and facilitate the identification of gaps and trends, namely: understanding the impacts of the conspiracy of silence on the accessibility of information on the family and the patient and analyzing the need for improvements in professional training and communication practices.

UNDERSTANDING THE IMPACTS OF THE CONSPIRACY OF SILENCE ON THE ACCESSIBILITY OF INFORMATION ON THE FAMILY AND THE PATIENT

The conspiracy of silence has a profound impact on both the patient and their families, as it directly affects communication and understanding about the process of illness and death. For the patient, the silence around his clinical status prevents him from having a clear view of his situation, making it difficult to make conscious decisions about his own care. This lack of transparency can generate feelings of isolation, anxiety, and frustration, since the patient realizes that something is being hidden, but does not have access to the truth of their condition.

For family members, the conspiracy of silence can generate confusion and uncertainty as to the real state of health of the loved one. Without accurate information, family members may not understand the seriousness of the situation, which prevents them from emotionally preparing for the impending loss and offering adequate support to the patient.

The patient, by not being included in the discussions about his own treatment, may feel helpless and powerless, losing the opportunity to say goodbye to his loved ones in an appropriate way or to resolve personal issues. For the family, the absence of open dialogues about the situation can mean the loss of valuable moments of emotional and spiritual connection with the patient, in addition to making grief difficult, since the shock of death can be more traumatic without adequate preparation.

The conspiracy of silence can have a significant impact on access to information for both the palliative patient and his family, limiting the full understanding of the severity of the condition. By omitting or softening information, often with the intention of emotionally protecting the patient or family members, this practice can deprive the patient of making informed decisions about their care and preparing adequately for the end of life. This directly interferes with the right to autonomy, which is a fundamental ethical principle in medicine.

Silence can also compromise the patient's quality of life by making it difficult to communicate openly about their preferences, desires, and fears. Lack of information can lead to emotional distress, by preventing the patient from feeling included in the care process itself. In addition, without a clear dialogue, the patient loses the opportunity to organize personal issues and resolve pending issues before death, which can increase suffering in the final phase.

Finally, the conspiracy of silence directly impacts the relationship between the health team, the patient and the family, weakening mutual trust. A more transparent and open approach, which respects the right to information and frank dialogue, is essential to promote patient-centered care, ensuring both physical and emotional well-being, and allowing for better preparation for the end of life in a dignified and conscious way.

Transparency and honest dialogue are essential to strengthen these bonds and ensure that everyone involved is aware of what is happening and can act in a cohesive and informed manner.

In this way, the conspiracy of silence, by trying to protect the patient and his family, actually generates more harm than good. The lack of transparency prevents the patient from actively participating in their care decisions, which can result in feelings of powerlessness and isolation. Likewise, family members are disoriented and unprepared to face the reality of the situation, which can aggravate grief and make the farewell process difficult. Clear and honest communication is essential to provide a more dignified end of life and to strengthen emotional connections at such a delicate time. Thus, promoting open dialogue is not only an ethical issue, but also a way to offer emotional support to both the patient and the family.

ANALYZING THE NEED FOR IMPROVEMENTS IN PROFESSIONAL TRAINING AND COMMUNICATION PRACTICES

In order for the patient to be able to make informed decisions about their treatment and end-of-life care, it is essential that they are fully aware of their condition. In this sense, health professionals need adequate training to recognize the delicate line between emotional protection and the preservation of patient autonomy, ensuring that the patient has the right to understand and actively participate in his or her own care process.

Communication in palliative care is crucial to ensure the quality of care. Often, the conspiracy of silence arises from the difficulty of professionals in addressing sensitive topics in a clear and compassionate way. Structured training should offer professionals the necessary tools to conduct difficult conversations, respecting the time and emotions of the patient and family, without imposing information in an abrupt or insensitive way. This will allow professionals to better manage the emotional challenges of end-of-life, balancing patient care with preserving their own mental health.

In addition, the conspiracy of silence is often associated with cultural and family issues. Some cultures see the act of talking about death as something that can speed up the process or cause unnecessary suffering. Thus, professionals need to be trained to deal with these cultural variations, adopting a personalized and respectful approach, which takes into account the expectations and beliefs of families and patients.

DISCUSSION

Reasons why doctors and family members are hesitant to disclose some information to patients can include the psychological impact and pain arising from the treatment that patients face, especially the loss of physical integrity. The popularization of informing them of their diagnosis is increasing year after year, and the dissemination of the diagnosis is an independent protective factor, which helps to prolong survival time in patients in end-of-life care. Patients who are unaware of their true condition may develop unrealistic optimism, which can lead to an unhealthy lifestyle and thus worsen their situation (He *et al*., 2021). In contrast, having a clear perspective on the status of your cancer can lead to a healthier lifestyle (Jiang *et al.,* 2007).

As in the results of the present study, it is possible to perceive that some patients deal with their challenges and difficult moments related to receiving bad news and their serious illness with their religious beliefs and rituals. As a result, it has been suggested that conversations and discourses about bad news should incorporate these aspects of cultural values (Avalew *et al*., 2023). In line with this, studies have reported that patients want health professionals to consider and respect their religious values (Aminiahidashti *et al*., 2007).

It is often the desire of patients to delegate to their family how to cope with the prognosis of their disease (Shah *et al*., 2023; Abraha *et al*., 2021). However, others wished to discuss their medical conditions and receive bad news in the presence of family members (Avalew *et al*., 2023; Fisseha *et al*., 2020). However, they reported receiving insufficient information about their medical condition, as well as a negative experience when receiving bad news. Similarly, a quantitative study showed that patients with life-threatening illnesses obtained low levels of satisfaction with the information provided about their illness and approaches to delivering bad news (Fisseha *et al*., 2020).

Therefore, it is common for some more sensitive medical news to be shared with caution, which can lead to patients not always receiving complete information about their condition (Kebede *et al*.). However, by communicating more news, it opens up the opportunity for emotional issues, such as psychological pain, anguish and fears, in addition to enabling access to appropriate support (Alzahrani et al., 2018).

Rates of quality of life, anxiety, and depression were no better in those who were unaware of their cancer diagnosis compared to those who were aware (Alsirafy *et al*., 2022). Awareness of cancer diagnosis is associated with significant psychological morbidity compared to lack of knowledge (Tavoli *et al*., 2007). On the other hand, some studies have found no difference in psychiatric morbidity between aware and unaware patients (Wang *et al*., 2014; Qian *et al*., 2016). In addition, in another study, unaware patients had significantly higher anxiety and depression scores (Chittem *et al*., 2013).

The interplay between multiple factors, such as fear of death, information received, and symptoms, which collectively influence belief in curability and interest in low-efficacy therapies, underscore the importance of improving communication between healthcare providers and patients to ensure a fully informed approach and ethical treatment decision-making (Carmona-Bayonas *et* al.2023).

Graduate achievement, in-service training in end-of-life care, and training in intensive care unit settings were found to be independent determinants of improved end-of-life care competencies. However, only about a quarter of the study population received any form of training, thus reflecting deficiencies in knowledge and attitudes related to palliative care (Chang *et al*. 2021). The inconsistency of structured end-of-life care curricula as an integral part of medical training, variability in exposure to patient care, and lack of opportunities to practice skills under supervision have been identified as universal causes of palliative care competency mismatch (Schroder *et al*., 2009; Hyley *et al*., 2018).

Palliative practitioners need to be assertive when communicating with a family member or a member who has opted for the conspiracy of silence while at the same time demanding that the team come to an agreement, based on what is best for the patient. Training is important to improve communication skills such as active listening, assertive training, conflict resolution and negotiation, and the dissemination of bad news using recognized protocols (Grilo AM, 2012).

The care team is responsible for supporting and creating an ideal communication channel for the family member to reflect on the disease and express the suffering experienced (Wittenberg et al., 2018) in addition to offering support to prevent or alleviate the patient's suffering until the end of their life (Rodriguez, 2014; Ferreira *et al*., 2024).

Person-centered care is of great importance, taking into account the family as an integral part of patient care. In addition, it is of paramount importance to use a comprehensive approach to care during the end-of-life process, with a compassionate view of professionals as an integral and necessary part of the emotional and spiritual accompaniment of the patient-family dyad (Garcia-Navarro *et al*. 2023).

Communication can be considered an essential part of the human being and needs to be attended to by the professionals who accompany them during the end-of-life process, both in the case of the patient and the family. Communication is the fundamental tool of health professionals, and this tool becomes much more powerful when we are faced with communication with the patient and family during the end-of-life process. The way to communicate with a patient in palliative care and their family will define the type of relationship that will be established. This situation requires that the health professionals who care for them have skills for physical, emotional and spiritual accompaniment. Communication acquires, at this moment, the essence of comprehensive care and is part of the established means of the helping relationship (Lisa, Bristowe, 2016; Tarberg *et al*., 2019).

The need for professional communication is evident as a tool to assist expression, both by people during the end-of-life process and by the family members who care for them. This communication allows caregivers to feel safe in care, while helping them face their fears in the face of the death of their loved one and allowing them to grow during the process of acceptance at this stage (Garcia-Navarro *et al*. 2023).

CONCLUSION

The conspiracy of silence, by omitting information about the health status of patients in palliative care, can limit their autonomy and make it difficult to make conscious decisions about their treatment. This practice, often motivated by cultural and emotional issues, also negatively impacts the family, which may not be prepared to deal with the severity of the situation.

It is critical that healthcare professionals are trained to balance emotional protection and sensitive information delivery while respecting cultural and religious beliefs. Effective and transparent communication not only strengthens trust between patient, family, and medical staff, but also contributes to patient-centered care, promoting both physical and emotional well-being in the final moments of life.

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