Bad News Communication in Palliative Care and the Conspiracy of Silence in Oncology Care

Comunicação de Más Notícias em Cuidados Paliativos e Conspiração do Silêncio na Assistência Oncológica
Comunicación de Malas Noticias en Cuidados Paliativos y Conspiración del Silencio en la Atención Oncológica

RESUMO

Objetivo: Analisar, a partir de um relato de experiência discente em serviço de oncologia, as implicações da conspiração do silêncio na assistência. **Método:** Trata-se de pesquisa qualitativa, baseada em vivências de estágio curricular, registros em diário de campo, diálogo com equipe multiprofissional e revisão da literatura. **Resultados:** Observou-se que familiares frequentemente solicitam a omissão ou restrição de informações relativas ao diagnóstico e prognóstico, limitando a autonomia do paciente e impactando a tomada de decisões. **Conclusão:** Evidencia-se que estratégias como escuta ativa, empatia, reuniões familiares e uso de protocolos estruturados fortalecem o vínculo terapêutico, favorecem a compreensão e qualificam a assistência paliativa.
DESCRITORES: Comunicação em saúde; Cuidados paliativos; Oncologia; Equipe Multiprofissional.

ABSTRACT

Objective: To analyze, based on a student's account of their experience in an oncology service, the implications of the conspiracy of silence in healthcare. **Method:** It is a qualitative study grounded in curricular internship experiences, field diary records, dialogue with a multidisciplinary team, and literature review. **Results:** Findings indicate that family members often request the omission or restriction of information regarding diagnosis and prognosis, thereby limiting patient autonomy and influencing decision-making processes. **Conclusion:** Evidence suggests that strategies such as active listening, empathy, family meetings, and the use of structured communication protocols strengthen the therapeutic relationship, enhance understanding, and improve the quality of palliative care delivery.
DESCRIPTORS: Health Communication; Palliatives Care; Medical Oncology; Multidisciplinary Care Team.

RESUMEN

Objetivo: Este estudio tiene como objetivo analizar, a partir de un relato de experiencia estudiantil en un servicio de oncología, las implicaciones de la conspiración del silencio en la práctica asistencial. **Método:** Se trata de un estudio cualitativo basado en vivencias de prácticas curriculares, registros en diario de campo, diálogo con el equipo multidisciplinario y revisión de la literatura. **Resultados:** Se observó que los familiares frecuentemente solicitan la omisión o restricción de información relacionada con el diagnóstico y el pronóstico, limitando la autonomía del paciente e influyendo en la toma de decisiones. **Conclusión:** La evidencia sugiere que estrategias como la escucha activa, la empatía, las reuniones familiares y el uso de protocolos estructurados fortalecen la relación terapéutica, favorecen la comprensión y mejoran la calidad de la atención paliativa.
DESCRIPTORES: Comunicación en salud; Cuidados paliativos; Oncología; Equipo multidisciplinario.

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INTRODUCTION

Cancer is a group of diseases characterized by the disordered multiplication of cells in the body, forming tumors that compromise the functioning of tissues and organs. In more severe cases, metastasis occurs, a process in which malignant cells spread from the primary tumor, reach blood or lymphatic vessels, and spread to other parts

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of the body, giving rise to secondary tumors, which makes treatment more complex[1].

This pathology is considered a serious global public health problem due to its high incidence and mortality. When a cure is no longer possible, palliative care becomes essential. Palliative care (PC) emerges as a response to the needs and challenges inherent in serious, progressive, incurable, and limiting diseases, as it is an essential care model for promoting the quality of life and well-being of patients, preserving their dignity and prioritizing a comprehensive and person-centered approach[2].

The Ministry of Health's PC Manual emphasizes the importance of alleviating suffering by reducing physical, mental, and spiritual pain through integrated action between the healthcare team, the patient, and their family members. It is an intervention that requires a careful and precise approach, aimed at promoting the comfort of all those involved in the process, favoring a better coping with the disease through the continuous improvement of the care provided and attention to the constant psychosocial and economic changes that the oncological diagnosis addresses[3].

Bad news is understood as any negative information that causes a possible change in a person's life due to a specific situation, such as the need to change the course of treatment, poor response to treatment, the need for hospitalization or invasive procedures, loss of functionality, deprivation of social participation, and inevitable lifestyle changes[4].

In this regard, effective communication in PC, in the context of oncology, helps in understanding the health condition and the best course of action regarding treatment options, favoring the clarification of doubts and adherence to therapy, always based on clarity and transparency, aiming at a relationship of trust with the healthcare team[5].

Furthermore, communicating bad news is one of the most delicate moments in the practice of any healthcare professional. It involves not only conveying difficult information, but also creating a space where suffering can be welcomed with empathy and respect[6].

When the dialogue involves the exhaustion of therapeutic possibilities in the face of advanced and incurable disease, the emotional impact tends to be profound, affecting both the patient and their family members. This reality can compromise physical and psychological well-being, in addition to restricting perspectives and decisions related to the future. Faced with this experience, patients and families are challenged to reframe the experience, seeking new ways to understand and face uncertainty, which requires constant adaptation and reconstruction of meaning.

In this process, silence often manifests itself in the early stages of CP, constituting a recurring social phenomenon that involves patients, family members, caregivers, and the healthcare team[9]. Although finitude is inherent to the human condition, patients, family members, and multidisciplinary healthcare teams daily demonstrate communication difficulties, sometimes resorting to the so-called conspiracy of silence. This strategy consists of avoiding discussions about health status, prognosis, and finitude, fearing the emotional repercussions that knowledge of this information may cause[10-11] .

Given the impact of this phenomenon on healthcare, this report aims to describe the student experience during undergraduate studies in the context of oncology CP and communication, focusing on the phenomenon of the conspiracy of silence, seeking to analyze its implications in the communication process between the health team, the patient, and their family members, as well as its repercussions on decision-making, the experience of illness, and comprehensive care in the face of diagnosis.

METHOD

This is a qualitative and descriptive study, characterized as an experience report, developed from dialogues and experiences shared with students and professionals from a multidisciplinary team working in CP.

The experiences analyzed emerged from interactions that occurred during informal exchanges in the daily routine of the service, as well as during discussions of clinical cases, in which perceptions, care strategies, and ethical challenges related to the pact of silence regarding the prognosis of patients were shared.

The records were produced in April 2024 by students in the undergraduate nursing program during the mandatory internship for the course Comprehensive Adult Health Care II, whose syllabus covers comprehensive adult care, including clinical assessment and care in acute and chronic health conditions. The inclusion of students in this context enabled them to become familiar with CP care practices and health communication processes.

The setting for the experience was an oncology service located in southern Brazil, a reference in the care of patients with oncological diseases at different stages of clinical evolution. The observations and experiences were recorded in a field diary, containing descriptions of interactions, analytical reflections, and aspects relevant to understanding practices related to prognosis communication and the pact of silence.

The material was analyzed

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through a thorough and systematic reading of the records, followed by the identification of thematic axes that emerged from the experience, especially those related to communication in CP, the ethical aspects of care, and the repercussions of the pact of silence on care. The interpretation of the findings was based on the theoretical assumptions of CP and bioethics, in dialogue with the scientific literature relevant to the topic.

RESULTS

This experience report describes observations and academic experiences developed in the context of palliative care. The practical internship, with a total workload of 15 hours, was carried out in an oncology service (outpatient clinic) responsible for monitoring patients in oncological palliative care.

In the outpatient setting, ten patients were seen during the period. It was observed that patients maintained greater contact with their family and social routine, which favored the preservation of autonomy and personal identity. Unlike the hospital environment, the outpatient clinic allowed for more longitudinal and flexible care, with greater possibility for continuous dialogue between the team, patient, and family members.

The most significant experiences were related to the follow-up of patients and their families after the communication of the cancer diagnosis, recurrence of the disease, or confirmation of therapeutic ineffectiveness in relation to the previously instituted treatment.

In several situations, it was possible to observe intense emotional manifestations, such as denial, anxiety, anger, and prolonged silence after the consultation. In some cases, family members requested a private meeting with the team to discuss the prognosis without the patient present, revealing uncertainty about the best way to communicate the news.

It was observed that the experience of CP varied according to factors such as social class, age, gender, and family structure. Patients with a larger support network showed greater adherence to guidelines and better organization of home care. In contrast, families with previous conflicts or emotional overload showed greater difficulty in making shared decisions.

In elderly patients, it became evident that the family often assumed the role of primary interlocutor with the team, mediating information about diagnosis, prognosis, and treatment. Although motivated by protection, this attitude sometimes resulted in the omission of information relevant to the patient.

During the internship, the case of an elderly patient with progressive metastatic lung cancer undergoing his first palliative chemotherapy infusion, accompanied by his daughter and granddaughter, was followed. The family took full responsibility for communicating with the team, answering questions directed at the patient and explicitly requesting that certain information about the prognosis not be passed on to him.

At one point, when the professional sought to assess the patient's understanding of his clinical condition, his daughter intervened, stating that he did not know that the disease was advanced and that she preferred him to remain unaware. The patient was observed to be introspective, paying close attention to the conversations, suggesting a possible perception of the seriousness of the situation, despite the attempt to conceal it.

In contrast, there were also situations in which open communication produced positive effects. In a consultation conducted by a trained professional, principles similar to those of the SPIKES Protocol were adopted. Initially, the level of understanding of the patient and family about the illness was investigated; then, the information was conveyed gradually, with pauses to accommodate emotional reactions.

During this consultation, the patient verbalized his fear of “suffering alone” and his concern for his wife. Active listening allowed for the joint development of a care plan, including psychological support and guidance for the family. After the consultation, family members reported feeling more secure and prepared.

The internship highlighted weaknesses in the preparation of professionals for communicating bad news. Some team members showed insecurity, used overly technical language, and had difficulty managing intense emotions. There was also a lack of structured family meetings in certain cases, which could have helped to better align information.

These experiences prompted reflections on the need for greater training in PC communication during academic training, including methodologies such as realistic simulation and specific training for communicating difficult news.

Similar situations occurred in other consultations, in which family members requested that terms such as “metastasis,” “progression,” or “palliative care” not be used. This behavior evidenced the presence of the so-called siege of silence, characterized by the attempt to protect the patient from emotional suffering.

DISCUSSION

The phenomenon observed in the outpatient clinic corresponds to what is described as a conspiracy of silence, characterized by evasion or reluctance to openly discuss the di-

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agnosis and prognosis[12]. The literature shows that the absence of honest communication can compromise quality of life, interfere with decision-making, and result in unnecessary invasive interventions[13].

Studies indicate that patients who are unaware of the severity of their condition do not have better quality of life, anxiety, or depression scores[14]. Furthermore, lack of knowledge can lead to unrealistic optimism and behaviors that are harmful to health[15].

Excluding patients from discussions can result in feelings of helplessness, loss of autonomy, and the inability to resolve personal and emotional issues, also impacting the family grieving process[16] .

Jean Watson's Transpersonal Care Theory maintains that care should be based on ethical, humanistic, and relational principles. From this perspective, the pact of silence weakens transpersonal care by limiting dialogue and patient autonomy[17].

Communication, therefore, should not be restricted to the transmission of information, but should constitute a space for the construction of meaning, the acceptance of suffering, and the preservation of dignity. The study by xxx reinforces that the siege of silence is often associated with cultural and family factors[16]. Thus, overcoming this phenomenon should not occur through imposition, but through structured dialogue, active listening, and building understanding with the family[18].

Strategies such as structured family meetings, the use of reflective questions (“If you were in his/her place, would you want to know?”), and the participation of a multidisciplinary team demonstrate potential for deconstructing the pact of silence without breaking emotional bonds.

The use of the SPIKES Protocol is relevant in conveying difficult news, comprising six fundamental steps that favor gradual communication, emotional support, and joint care planning[20]. Complementarily, the NURSE protocol assists in managing emotions, guiding professionals to name feelings, understand fears, respect, support, and explore emotions[21].

The experiences observed during the internship confirm scientific findings that associate honest communication with greater satisfaction and safety for patients and their families[22].

The training gap identified in health courses converges with the literature, which points out that only a small portion of professionals receive specific training in PC[23] . Realistic simulation has been identified as a promising strategy for the development of communication skills, although consolidated structural guidelines for its implementation are still lacking[24-25] .

CONCLUSION

This experience report shows that communication in oncological PC is a central axis for promoting comprehensive, humanized, and ethical care, especially in the face of the phenomenon of the conspiracy of silence. The academic experiences described allowed us to understand that the omission or distortion of information, although often motivated by the desire to protect the patient, can have significant negative impacts on quality of life, autonomy, decision-making, and the process of coping with illness and finitude, both for the patient and their family members.

It was observed that the siege of silence emerges from a multifactorial context, permeated by cultural, emotional, family, and institutional aspects, requiring health professionals to have sensitivity, technical preparation, and advanced communication skills. In this sense, communication should not be understood only as the transmission of information, but as a relational process based on active listening, welcoming emotions, and shared decision-making, respecting the values, beliefs, and limits of each individual and family.

The report reinforces the importance of multidisciplinary action and the use of structured strategies, such as family meetings, reflective questions, and protocols for communicating bad news, such as SPIKES and NURSE, as tools to facilitate dialogue and reduce the impacts of the pact of silence. Furthermore, there is a clear need for greater investment in the academic training and continuing education of healthcare professionals, systematically incorporating content related to palliative care, bioethics, and communicating bad news, including through active methodologies such as realistic simulation.

Finally, it should be noted that overcoming the conspiracy of silence does not occur in an imposing manner, but through dialogical, empathetic, and gradual processes capable of strengthening bonds, promoting patient dignity, and ensuring person-centered care. Thus, it is hoped that this report will contribute to critical reflection on communication practices in palliative care and encourage the development of more sensitive, ethical, and humanized approaches in the context of oncology.

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