Original Article

Conspiracy of Silence in Palliative Care: A Concept Analysis

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Abstract

Background and Aim: With chronic diseases on the rise, there is a growing demand for palliative care. The global landscape of the integration of palliative care into health-care systems is incipient, which leads to a lack of social awareness of this reality and consequently, to communication failures, particularly a conspiracy of silence. The aim of this study was to analyze the concept of conspiracy of silence in palliative care. **Materials and Methods:** Walker and Avant method of concept analysis was used. Review and synthesis of literature supported the analysis process. Forty-seven articles were analyzed. **Results:** Results showed that the conspiracy of silence in palliative care is a communication failure, typical of limited life expectancy prognosis, and involves patients, their families, and health-care teams. Lack of autonomy, overburden, family malfunctioning and coping, and health-care dehumanization are consequences of the conspiracy of silence in palliative care. **Conclusions:** The present study had found that scales to measure this concept as well as interventions that consider important factors in the communication process in palliative care identified in this analysis are needed.

Keywords: Communication barriers, concept formation, palliative care

Introduction

Noncommunicable chronic diseases are on the rise and so is the need for sound health-care systems able to address these diseases.[1] Long duration and progression of these conditions result in situations where health personnel or family members are at times unaware of the proximity of death. However, there are other circumstances where both health personnel and family members know about the disease progression, but a sort of agreement of silence is reached to avoid alerting the patient to the proximity of the end, a situation known as conspiracy of silence.[2]

Palliative care shows an incipient development in several parts of the world. Collective imagination about palliative care in health-care systems is related to an exclusive right for patients with terminal illnesses or neoplastic diseases.[3] Low development and low integration of palliative care into both health-care systems and people's daily lives result in limited social conscience on this matter. This situation leads to collective imaginations about disease, end of life, and death as unnatural scenarios of suffering, which trigger communication and coping failures among all people involved in in the process of caring for the patient at the end of life.[3,4]

The conspiracy of silence in palliative care is a common manifestation, and it is due to communication failures in this scenario. It has different demonstrations in terms of its causes, characteristics, consequences, and the people involved in the agreement; these aspects are highly complex and pose a great challenge for a proper approach to this concept.[5-8] Despite its importance in palliative care, a characterization of the concept "conspiracy of silence" that includes definition, characteristics, triggers, consequences, and means of assessing does not exist in any study. Therefore, a clear definition of this concept will allow health professionals working in this field to recognize and respond promptly to a conspiracy of silence in palliative care. This study is thus intended to clarify the concept of "conspiracy of silence" in palliative care as well as its characteristics and related aspects.

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Materials and Methods

A concept analysis was conducted following the method proposed by Walker and Avant.[9] The objective of this method is to explore, clarify, validate, and define a concept through a formal and rigorous process of scientific inquiry. Using this method, we hoped to obtain a more precise and operative definition that allowed us to increase the validity of the concept in practice and to facilitate its identification, approach, and differentiation from other similar concepts. This concept analysis observed the following steps: (1) selecting the concept of interest "conspiracy of silence," (2) determining the objective of the analysis that was to construct a theoretical definition of the concept, (3) identifying all definitions and usage of the concept, (4) identifying and determining all critical attributes of the concept, (5) identifying antecedents and consequences, (6) defining empirical referents, and (7) describing model, borderline, and contrary cases.

A review of scientific literature was conducted to identify definitions and usage, as well as to determine attributes, antecedents, consequences, and empirical referents. It included a systematic search in LILACS, Scielo, Cuiden, Sage, Willey Online Library, Scopus, ScienceDirect, Medline, and ProQuest databases. For this search, the keywords silence, conspiracy, pact, palliative care, and truth disclosure were used. The search was narrowed down to articles published between 2000 and 2017 and written in English or Spanish.

The selection process of primary sources included reading titles and abstracts and evaluating the quality of the articles. In the first review, 342 potentially relevant articles were retrieved. After reading their titles and abstracts, 172 articles were excluded, and after skimming the whole text of the remaining 170 articles, 47 articles were selected. The rest of them were excluded as they addressed other topics or were repeated publications. To determine the scientific quality of the articles, a critical appraisal of the 47 articles was conducted following Burns and Grove guidelines.[10]

Findings were taken from each author separately. Then, during joint working sessions, the findings were discussed, compared, and finally included in each category as proposed by Walker and Avant.[9] To identify contrary, borderline, and model cases, we discussed situations experienced in practice in the field of palliative care, when a conspiracy of silence was either implied or expressed, the patient cases were theoretical.

Throughout the review process, respect for intellectual property was pursued.[11]

Results

Definitions and usages of the concept conspiracy of silence

According to the Farlex Dictionary of idioms, a conspiracy of silence is "an agreement, either explicit or unspoken, among members of a group to keep secret certain information that, if exposed, could be damaging to the group, its interests, or its associates."[12]

In Spanish, the concepts "conspiracy of silence" and "pact of silence" have been used interchangeably in areas related to health-disease processes, politics, and education.[13-15] Similarly, these concepts have been used without distinction in palliative care because there is still no agreement on the appropriate terms that should be used to refer to the silence related to the health condition and the disease progression of a person in a palliative stage of a disease.[16,17]

Some authors report that the term "conspiracy of silence" refers to the agreement reached by family members or professionals under supervision of health institutions, either explicit or unspoken, to alter the information provided to the patient. This agreement involves not expressing negative feelings or insubstantial optimism in order to conceal the diagnosis, prognosis, or seriousness of the situation, based on ideas of lessening concern or anguish over proximity of death, protecting the family, and avoiding emotional outbursts.[17,18]

Regarding the pattern in the types of conspiracies, it is important to mention that according to the agents' involvement in the conspiracy of silence, its modality can be determined. That is to say, there is an adaptive conspiracy of silence when the patient is the person who denies, avoids, does not speak, or does not want to know their diagnosis or prognosis.[16,19]

On the contrary, there is a maladaptive conspiracy of silence when the family and health professionals are the ones who find it difficult to establish clear communication techniques. At the same time, the attitude of the agents involved may motivate this process, as family members could be those who do not answer or withhold information from the patients when they ask questions. However, the health-care team could also develop this behavior pattern when they notice a passive attitude of patients and their families.[16-19]

It is important to point out that both family members and health-care teams produce different degrees of information disclosure. On the one hand, there are absolute conspiring concealers absolute conspirators who withhold all data, facts, seriousness of disease, diagnostic details, disease progression, and disease prognosis from the patients; on the other hand, there are partial conspiring concealers who inform the patients about diagnoses, but they refuse to receive or give any information about prognoses.[16,19]

There are studies written in Spanish that affirms that it is not possible to speak equally of "conspiracy" and "pact" since the agents involved in a "pact of silence" (Concept in Spanish) (i.e., patients, family members, palliative care professionals, and health-care institutions or private health insurers) know patient's diagnosis, prognosis, and/or seriousness of the disease, but they avoid talking about it. In other words, they suggest that "conspiracy of silence" should be used to refer to omission of information, and "pact of silence" to refer to situations when, despite having information, one omits to disclose it.[20,21]

Defining attributes

The following attributes of the concept "conspiracy of silence" in palliative care were identified from the literature review:

1. Difficulty in communicating verbal and nonverbal information, perceptions, representations, or emotions related to patient's disease process in palliative care[17,18,22,23]
2. Full or partial omission of information about patient's disease process in palliative care[16,19]
3. Avoidance talking about issues related to the disease during communication with a person who needs palliative care[16,18]
4. Simultaneously unfolding pattern that involves two or more of the following agents: patient, family, and health-care team.[20,21,24]

Antecedents

Palliative care patients may reach a disinterested conciliation between what society expects and what reality presents to them and which is why they deny and avoid or they do not talk or seem not to want to know about their situation.[16,19,21,25,26] Nevertheless, the reasons for these phenomena of conspiracy of silence generally steam from passive attitudes, indifference to confirmation of a fatal diagnosis, unrealistic expectations of recovery, and the patient's unmet need to ask questions because care is provided by different health professionals and it wanes any interest in establishing an assertive communication process.[25,27,28] It is worth noting that a conspiracy of silence is common when a person is facing an impending death prognosis and is regarded as vulnerable. It happens, especially with older adults, children,[6] and adolescents.[29]

Regarding a conspiracy of silence organized by family members, aspects such as expectations of patient's improvement or recovery, expectations of returning to preillness life, importance of patient's family role, socioeconomic implications of patient's absence, and an implicit decision on adopting a passive attitude made by family members correspond directly to antecedents that trigger a conspiracy of silence.[30-33] The literature also reports that a conspiracy of silence between family members is more frequent among women, people with below secondary education, and people over 65-year-old.[20,30,31,34]

Values and beliefs in disease and death process are cross-cutting factors in a conspiracy of silence. It is often based on the belief that information omission and communication avoidance during the disease process make the burden and the worsening of the disease more bearable.[17,18,20,34]

Although all family members generally play an important role in this phenomenon of silence, a central agent in many cases can modulate the pattern of the conspiracy of silence in palliative care, namely, the main family caregiver. Due to the close bond between palliative care patients and their family caregivers, caregiving dynamics in some cases can revert to silence. Silence in family caregivers may be preceded by role overburden, scarce and ambiguous information, poor decision-making skills, fear of negative repercussions of truth disclosure,[30,35,36] overprotective attitude and paternalism, unsteadiness in the face of the thread of losing a loved one,[20,36] and inability to convey the message received from the health-care team.[37] Silence may be also preceded by perceptions of not being competent to provide care to the person and sometimes by underestimation of the information provided by the health-care team about the person's process.[28,30]

Regarding the health-care team, literature reports that formal learning is mainly based on a biologistic perspective, which is insufficient for the development of communication skills.[38] This makes it difficult to establish assertive communication processes in palliative care situations.[16,31,39] Nevertheless, it is worth noting that there are factors that are related to moral judgment and ethical dilemmas of the health-care team, such as difficulty of facing their emotions, proceeding through compassionate and deterministic attitudes to perpetuate an individual's life, feelings of frustration at not being able of providing the patient with a curative treatment,[40,41] avoiding expressions of affection, supporting family's decision to withhold information implicitly or explicitly from the patient, relying on family's manifestations about the patient's wishes,[37] stress, time pressure to attend to emotional needs of patients and their families, fear of being negatively impacted, difficulty of diagnosing a terminal illness, prognosis uncertainty,[42] hopelessness feelings,[43] and underestimation of patients' information needs.[31,39,40,44]

However, not all of the responsibility in the conspiracy of silence in palliative care falls on health-care teams. According to the literature reviewed, influence exerted on this phenomenon by health institutions is consistent with guidelines such as laws on productivity, failures in functioning and structure of health-care systems, patient objectification, staff burnout, and disruption of the therapeutic relationship due to indiscriminate use of medical technology.[21,24]

Consequences

It is evident that the conspiracy of silence in palliative care has important consequences, and in most of cases, such consequences negatively affect patients and their families.

Feelings of fear, anxiety, confusion, depression, unnecessary suffering, incomprehension, anger, and deceit are common in palliative care patients who face their relatives' silence. At the same time, these feelings prevent them from reorganizing and adapting to new situations and cause incapacity to conclude matters pending, loss of interest in life, increase in pain perception threshold, unrealistic expectations of recovering, and deprivation of their right to exercise their freedom with responsibility at the end of their lives.[29,30,35,45-47] It is worth mentioning that patients prefer to know their prognoses and withholding it from them can cause stress, worsening in quality of life,[48] and loss of autonomy and opportunities to be part of the decision-making process.[37] In addition, it can cause patients to receive insufficient treatment for refractory symptoms and their spiritual needs to be neglected.[37]

Partial or absolute conspiring families usually refuse to accept a possible death. Thus, they set silent patterns that trigger

communication blockages in the family system. This action generally provokes family members to grow apart from each other and difficulty or psychological incapacity for elaborating mourning, before and after the death of the loved one.[16,19,20,22,35]

The conspiracy of silence also affects health-care systems. By establishing a communication barrier around the true nature of the condition, connection failures among health-care teams, patients, and their families are favored. It hinders an appropriate care process or causes failures in ongoing care and a breakdown of multidirectional communication.[24]

Finally, the scope of a conspiracy of silence within the health-care team brings as a consequence dehumanization of the end-of-life care process.[36] This is evidenced by expressions of dissatisfaction at the care received by patients and their families.[37]

Empirical referents

The literature reviewed does not report specific empirical referents to measure the extent of a conspiracy of silence in palliative care. It evidence the need for further clarification and description of its attributes to define an empirical referent that allows making it objective. In their study with family members and patients at the end of life, Bermejo *et al*.[16] assessed the conspiracy of silence using two referents as follows: the first one was the degree of knowledge, which was categorized in a scale of "not knowing," "knowing intuitively," and "knowing" and the second one was patients, family members, and professionals attitudes. Both referents were categorized according to a psychological interview.

Since the conspiracy of silence in palliative care is a phenomenon that simultaneously involves several agents, its assessment becomes more complex because it is a collective event. However, as the conspiracy of silence is considered a failure in communication processes, there are empirical referents based on the measurement of communication skills that tangentially approach to an assessment of this phenomenon. The most common scales used in palliative care research are the following:

1. The communication skills rating scale used in different studies to assess communication skills of palliative care nurses[49]
2. The perceived competence questionnaire used by physicians to self-assess their communication competence in key end-of-life aspects, such as spiritual needs, treatments, maintaining hope, fears about the end of life, and do not resuscitate orders[50]
3. The silver scale, which assesses the communication skills in critical care settings at the end of life. Its domains address issues such as seeking information, assessing life values, educating family, extending care in a consistent manner, and responding to family questions[51]
4. The quality of communication questionnaire, which evaluates the quality of communication in professionals and families of seriously ill people[52,53]
5. The FAMCARE-patient scale, which measures patient's satisfaction with the palliative care they receive and includes communication with health-care providers.[54]

Identifying a model case

A patient is a 26-year-old woman diagnosed with pancreatic cancer and receiving palliative-intent treatment. Her prognosis is estimated to be <1 month to live, and her main caregiver is Carmen, her mother. She has been suffering from refractory pain for a week now. She stays in the hospital hoping that she will be discharged soon and completely recovered so that she can go and see Stephany, her 6-year-old daughter, who lives in a town 10 h away and is being cared for by her relatives. The specialist physicians assume that she already knows her prognosis because it was informed to Carmen 2 weeks ago. Meanwhile, the nurses avoid discussing the prognosis with her because they think that she is out of their competence. Carmen is very sorry for her daughter and is unable to tell her that she is going to die soon.

Identifying a borderline case

A patient is a 38-year-old male diagnosed with amyotrophic lateral sclerosis. He has swallowing disorders and breathing is very difficult for him. He and his family know that he has little time to live. They have decided to reject mechanical ventilation, all invasive maneuvers, and resuscitation orders. They try to spend most of the time in family and avoid talking as much as possible about his prognosis and his quality of life because they prefer to take advantage of that time to live moments that will preserve his legacy after he departs. There is a family time to get his affairs in order before he dies, it is then when it is allowed to talk about his prognosis, but they avoid focusing on that only.

Identifying a contrary case

A patient is a 42-year-old male diagnosed with lung cancer who currently receives palliative-intent treatment. He knows that it is terrible news and he cannot do much to change his prognosis. However, he decided that his entire family should know what is going on, including his three children of 12, 8, and 5 years old. Despite his prognosis, He decided to live as fully as he can, as best he can. It involves departing as peacefully as possible, knowing that the people he cares about have his love, teachings, and will preserve his legacy, which is why he often talks with his wife, children, and other family members about this and the fact that he will be departing soon. He is no bothered by the fact that he is dying because he knows we are all going to die 1 day. He even thinks that he has the advantage over other people because he affirms that at least he suspects when it is going to happen, and forewarned is forearmed, as the saying goes.

Discussion

This article identified how the conspiracy of silence in palliative care occurs and the related factors that influence the process. According to the literature, the conspiracy of silence has a negative impact on patients and caregivers, which is

why health professionals must be attentive to identify the phenomenon and be able to intervene.

Health personnel, at all times during the care of the patient, should promote the prevention of the conspiracy of silence. One of the simplest actions to achieve this is honest communication between the health-care team and the patient and family,from the beginning of the relationship. This communication must be adapted to the needs of the patient and should include the caregivers, and family of the patient. In addition, it must be considered from the beginning of the disease, that it is the patient who makes the decisions about sharing information about the disease with other people.

On the other hand, when it is identified that there is a conspiracy of silence, it is important to ask about the reasons that generate this phenomenon without judging, and to explain and clarify the beliefs that patients and caregivers have. Questions like "why do you think it's better that he/she do not know anything?" They can help in this phase to explore those believes. Within the exploration it is important to evaluate the emotional burden that the conspiracy of silence brings for the family and patient and also the repercussions in other dimensions such as psychological, social and physical.

Finally, it is necessary to intervene in the conspiracy of silence in palliative care, so that the health personnel must have the necessary knowledge and experience to handle information about the disease and communication skills to establish a relationship of trust with both the patient and their relatives. Respect at all times the beliefs of the patient and family, and reconcile in this process is essential, as well as taking into account that the intervention must occur progressively and step by step to avoid feelings of fear or threat in the people intervened.

Conclusions

The conspiracy of silence in palliative care is a common phenomenon that affects patients, their families, and health-care teams. Silence can occur in two forms: as a conspiracy and as a pact. The conspiracy of silence generally involves family members and health-care teams who withhold full or partial information from the patient. On the contrary, in the pact of silence, both patient and family members, and even the health-care team, agree not to talk about patient's disease process, in spite of having this information. In either case, the agreements can be explicit or implicit.

The conspiracy of silence occurs due to communication failures caused by contradictions between what is expected and what actually occurs, unrealistic expectations, system of beliefs about illness and death, scarce or ambiguous information, fear of losing the loved one, poor caregiving skills, lack of training in communication skills, stress, overburden, and prognosis uncertainty.

The conspiracy of silence in palliative care has negative consequences for patients, mainly for their autonomy, decision-making skills, and quality of life. It also affects family functioning and coping and humanization of health care provided by health-care teams.

Scales to measure the concept of "conspiracy of silence" in palliative care were not found. Studies on this concept have been conducted using scales that tangentially assess "conspiracy of silence" by measuring communication skills. It is necessary to develop scales that allow assessing this concept.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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