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RESEARCH

Communication in palliative care: team, patient and family

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Abstract

Palliative care aims to fully take care and welcome patients and their families, in cases when cure of the disease is no longer possible, making use of good communication to improve quality of life. The study aimed to evaluate communication in palliative care and how it can influence the team-patient-family relationship. This is a qualitative, descriptive and exploratory research, involving six participants approached at a public health hospital in Suzano, in the State of São Paulo, Brazil. Data was collected through semi-structured interviews and were analyzed using the content analysis technique. It is concluded that proper communication is a relevant strategy for establishing a good team-patient-family relationship, however, it is necessary to identify other phenomena that are beyond the communicative skills of professionals. From a Bioethics perspective, communication stands out in healthcare and creates a bond that enables shared decisions.
Keywords: Communication. Palliative care. Bioethics. Chronic disease.

Resumo

Comunicação em cuidados paliativos: equipe, paciente e família

Cuidados paliativos visam acolher o paciente e sua família de forma integral em casos de impossibilidade de cura da doença, valendo-se de boa comunicação para melhorar a qualidade de vida. Este estudo objetivou avaliar a comunicação na assistência paliativa e sua influência na relação entre equipe, paciente e família. Trata-se de pesquisa qualitativa, descritiva e exploratória envolvendo seis participantes abordados em instituição hospitalar de saúde pública da cidade de Suzano, no estado de São Paulo. Dados foram coletados em entrevistas semiestruturadas e avaliados com a técnica de análise de conteúdo. Conclui-se que o diálogo adequado é estratégia relevante para estabelecer boa relação entre as três partes, sendo, no entanto, necessário identificar outros fenômenos que estão além das habilidades comunicativas dos profissionais. Na perspectiva da bioética, a comunicação se destaca na assistência e cria vínculo que possibilita decisões compartilhadas.
Palavras-chave: Comunicação. Cuidados paliativos. Bioética. Doença crônica.

Resumen

Comunicación en cuidados paliativos: equipo, paciente y familia

Los cuidados paliativos buscan cuidar al paciente y a su familia en forma integral en casos de imposibilidad de cura de la enfermedad, valiéndose de una buena comunicación para mejorar la calidad de vida. Este estudio tuvo como objetivo evaluar la comunicación en la asistencia paliativa y su influencia en la relación entre equipo, paciente y familia. Se trata de una investigación cualitativa, descriptiva y exploratoria, con seis participantes abordados en un hospital de salud pública de la ciudad de Suzano, en el estado de São Paulo, Brasil. Los datos se recogieron en entrevistas semiestructuradas y se evaluaron con la técnica de análisis de contenido. Se concluye que el diálogo adecuado es una estrategia relevante para establecer una buena relación entre las tres partes, siendo necesario, no obstante, identificar otros fenómenos que están más allá de las habilidades comunicativas de los profesionales. En la perspectiva bioética, la comunicación se destaca en la asistencia y crea un vínculo que posibilita las decisiones compartidas.
Palabras clave: Comunicación. Cuidados paliativos. Bioética. Enfermedad crónica.

Declaram não haver conflito de interesse.

Palliative care focuses not only on the life-threatening disease, but also on the patient, perceived as an autonomous and biographical being. It aims to improve the quality of life, control symptoms, and prevent physical, psychosocial, and spiritual suffering [1]. The treatment includes families during illness and at the moment their loved ones die [2].

Every patient suffering from active, progressive, and life-threatening diseases is eligible for palliative care, which is not restricted, as it is commonly believed, to terminally ill patients. This approach is also recommended for patients suffering from chronic and progressive diseases in different stages, changing only the amplitude of care and intervention, which must be consistent with the current phase of the disease and its natural process [1].

This practice emerged in 1967 with the modern Hospice movement lead by Cicely Saunders, a nursing, social administration, and medicine graduate, who identified patients suffering from incurable diseases and could not benefit from advanced medical therapies. Saunders devised a treatment model focused on care with a global view of those who suffer, addressing not only physical needs by minimizing pain and unpleasant symptoms, but also other sufferings that permeate the disease and the imminent possibility of death [3].

Communication and interpersonal relationships in palliative care are important modalities for ensuring full support to patients and their families, including unmet needs for high-tech medications and medical interventions. This welcome acknowledges the suffering of human beings and enables them to share their anxieties through appropriate techniques. New ways of coping with the current condition also emerge, minimizing anxiety and depression symptoms, in addition to promoting the patient's autonomy in times of significant change and loss [4].

Communication, verbal or not, is a fundamental instrument for health care due to the intersubjective relationship that permeate the interaction among team members, patients, and families. Verbal communication is characterized by thoughts and feelings expressed through words that facilitate the comprehension of something. Nonverbal communication encompasses the use of body language – gestures, glances, facial expressions, and even silence can convey messages in a given context. Both complement each other and make it possible to identify the explicit and implicit contents that an individual wishes to address [5].

Studies show that health professionals, especially doctors, learn to deal with diseases but not with patients This gap makes communication difficult because, in many cases, health professionals fail to realize that the way they address diagnosis and prognosis may affect patients during their illness and the treatment proposed, as well as family members and even physicians themselves [6].

Getting sick and the possibility of death torment a previously healthy body, causing patients and families to experience extreme emotional reactions towards suffering. Upon receiving bad news, it is common for the ill and their family members to experience intense emotions (pain, anger, crying, denial, anxiety, fear, worthlessness) that are often shown to the health team followed by complaints of abuse, neglect, disinterest, exaggerated demands, or hostility. In order to be managed, these reactions need to be correctly identified by health professionals [7,8].

The field of bioethics brings together important thoughts on ethical challenges that affect health care. It underpins issues related to patient autonomy while promoting the need for efficient communication to establish good practices in palliative care, in addition to enabling health professionals to understand that their actions often involve moral conflicts that require balance between resources and the organic condition of the patient [9]. This strand triggers discussions that contribute to improving health care and the interpersonal skills of physicians, patients, and families, being of extreme relevance for decision-making [10].

This study aims to evaluate the communication in palliative care and its influence on the relationship among the health team, patients, and families, considering the lack of knowledge about their communicative ability and the psychic phenomena that permeate such relationship. More specifically, it intends to: 1) verify the implications of communication in palliative care during the treatment process from the perspective of patients, families, and the palliative care team; 2) identify how each person involved perceive the communication established between the health team and the patient, and their opinion as to how it must be done; and 3) analyze the psychological phenomena of relationships and communication among staff, patients, and families in palliative care.

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Materials and method

This is a qualitative, descriptive, and exploratory research, which included six participants interviewed at a public health hospital in Suzano, a city located in the State of São Paulo. The study sample consisted of patients suffering from chronic diseases being treated at the hospital – regardless of the diagnosis – families, and members of the multidisciplinary team, who agreed to participate after signing an informed consent form.

Patients who lacked cognitive conditions to interact with researchers and family members; hospital staff who was absent on the days allocated for data collection or did not deal directly with patients in palliative care; and individuals who were not comfortable participating in the research were excluded. Two health professionals, two patients (hospitalized, conscious, and guided), and two family members participated in the research, totaling six reports. Patients were interviewed while laying on their hospital bed and screens were used to maintain their privacy. Family members and health professionals were interviewed in the office. In order to maintain the anonymity of the participants, the interviews were identified as Patient 1 and 2, Family Member 1 and 2, and Health Professional 1 and 2.

Data was collected between November 2017 and January 2018 after the approval of the Research Ethics Committee of São Camilo University Center. This study complied with the ethical norms and regulatory guidelines for research with human beings described in Resolution 466/2012, established by the Conselho Nacional de Saúde (CNS) (National Health Council) [11].

The empirical material was obtained in semi-structured interviews, with questions specifically prepared for health professionals, patients, and families. Three questions were addressed to health professionals: 1) In your opinion, what is it exactly team-patient communication? And how does it happen?; 2) Do you think that the communication and the relationship between staff and patients have any effect on their treatment? If so, in which way; 3) Talk about your relationship with patients and families. Four guiding questions were also prepared for or patients and families: 1) In your opinion, what is it exactly team-patient communication? And how does it happen; 2) How was it to receive information about your diagnosis? And how did the team convey the information? 3) Talk about your relationship with the health team; and 4) Do you think that the communication and the relationship between staff and patients have any effect on their treatment? If so, in which way?

The questions prepared for the semi-structured interview are based on theories and hypotheses related to the objectives of the research, and can be complemented with others, according to the answers provided by the participant. This type of interview allows freer answers, since they are not restricted to any standardization of alternatives, providing a broad and general view of the phenomenon researched [12].

Data was evaluated according to content analysis: a qualitative data investigation method that encompasses research techniques adapted to spoken and written material. The analysis consists of three steps: 1) pre-analysis, including data organization and theoretical construction of the research, proposing hypotheses and elaborating objectives; 2) exploration of the material, coding it based on record units; and 3) treatment of results and interpretation of data and/or content [13,14].

Results and discussion

Three thematic categories were contemplated in this study, whose content unveils the communication established in palliative care and its implications on the relationship among the health team, patients, and family members, also taking into account the perception of each one: 1) differences in individual understanding of communication and how the health team, patients, and family members think it must be conducted; 2) psychological phenomena involving the relationship and communication among the three groups in palliative care; and 3) implications of communication during treatment according to patients, family members, and the health team.

Differences in understanding communication and how it must be established

In this category, it is possible to observe that the participants understand the dialogue and procedures based on subjective references, that is, the values and individual concepts built upon their experiences and internal resources that cope with pain and suffering. The statements presented below expose a wide range of opinions, and some may even share similar aspects underlined by subjective peculiarities:

"I think the health team must speak only one language (...) *team members must talk among themselves* (...) *otherwise, they confuse patients*

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and their companions. I think that's it, it has to be a multidisciplinary team, even if they just talk to one another and reach a consensus" (Family Member 1).

"I think they must have good manners. If I was bed ridden and I was conscious, if someone treats me well, I will treat that person well; if someone treats me rudely, I will do the same. To treat well is to be polite; if the patient asks for something, do it immediately, do not leave it for later. There are people who have other problems and get to work in a bad mood. Do not mix things up and focus on the needs of the patient at that particular moment. Do things with love; show affection, respect" (Family Member 2).

"The best way to do it [communication] *is as a team during a meeting with everyone gathered together. It's more formal. It's not something done in the hallway – hallway talk is hard for us, not to mention bedside talk. In a meeting, each individual and each professional tell us about their specialty and what they will do with the patient, the prognosis, the treatment plan, so the family can be aware – not everyone realizes that. But once we share what we think with family members, the step-by-step treatment becomes much easier for us. The stress related to it is over all of the sudden. Obviously, someone in the family can ask a lot of questions, but we must be patient, as we are able to tell really quick which family member is more difficult and who is the one who will understand the situation much better and communicate with the whole family. The one who will be more cooperative"* (Health Professional 1).

Based on what each participant declared, it is possible to identify what each one understands of and prioritizes in communication in palliative care: linear transmission; one conducted with manners, affection, respect, and love; one that is carried out with care respecting the time patients and family members have available during the elaboration of bad news; communication delivered as a team and not individually to help patients better understand their situation and ensure the safety of health professionals, who would not be by themselves in times of tension and emotional vulnerability. Although some points are similar, each participant highlights their own view on the subject.

The way each participant builds his/her speech helps to identify their personalities and what is really important to them, as well as what they want to know and how they wish to receive information. Active and reflective listening is a fundamental instrument in palliative care to collect elements that can help communication and establish its limits, facilitating the therapeutic encounter [4]. For example, the two patients interviewed reacted differently to the process of chronic and irreversible illness, so it was possible to identify through their speech important data for the establishment of ethical communication that is indispensable for the bond between doctor and patient:

"I only got to know I was in the hospital after a week, about 10 days later. The doctor came and I asked him if he could tell what had happened and my condition" (Patient 1).

"Information should not be provided in such direct manner. Because it will be really bad if I find out I won't walk anymore. I mean, it's a big shock. So, they do not give you this diagnosis. Doctors don't know everything, only God knows" (Patient 2).

The speech of Patient 2 is very expressive given the possibility he might not be able to walk anymore. He uses the term "shock" and thinks that communication should not be done directly, expressing his thoughts on how much he can take in regard to his current situation. Patient 1 initialized contact by authorizing the doctor to talk about his diagnosis and prognosis.

The difference between the two demonstrates how one perceives and faces the world around them. Two people do not share the same life story, and the subjective constructions are permeated by the experiences and memories that are established in the particular semantics of each being. Such references should not be interpreted as better or worse, but the differences that exist in any relationship must be identified [15]. Disregarding them may lead health professionals to generalize the communicative act and to establish preconceptions. This is the reason why so many obstacles are imposed upon the relationship with patients and families, mostly due to misunderstanding and failure to understand each other's wishes and personalities, which health professionals usually define right away according to their own standards and for believing that they to know more about their patients than the patients themselves.

The guidelines may vary, but listening must always be the first step, as it enables health professionals to evaluate the best way to communicate in each case based on what is known about patients and/or family members. Listening can minimize anguish, conflict, and delusional thoughts

arising from what patients think about their health condition, the opinions of family members, and those of health professionals, who make assumptions based on their own particular world [16].

Much more than talking, knowing how to listen leads communication to the real need of the patient, allowing them to freely express their wishes. This shows respect towards patients and their knowledge, which helps them to better understand their own situation and the prerogative of establishing the limits of what they want to be aware. It is true that every patient has the "right" to know, but not everyone "needs" to know [17].

Bioethics considers autonomy as primordial for human well-being and dignity. It plays an active role during the discussions about diagnosis and prognosis, helping patients to better understand their situation and regain their dignity. Hence, communication has taken a prominent position in health care, strengthening the relationship with patients and families, and favoring shared decisions [18].

The scenario of intense pain to which patients, family members, and health professionals are exposed influences the communicative process. Like patients and their families, health professionals often use defense mechanisms that lead them not to pay attention to the gravity and impact of their speech, either by how or when they disclose information. They also fail to realize that distancing themselves from patients and families can be a reaction towards an uncomfortable situation that may cause irreversible effects on the receiver and the relationship previously established [6].

Psychological phenomena between relationships and communication in palliative care

Although it is possible to infer the good communication among all the participants based on all the recommendations for appropriate palliative care, it was observed that, in some cases, the response of patients and family members was not satisfactory. This leads the health team to question their conduct, which generates insecurity, anguish, and a troubled relationship:

"I don't think we are able to keep every family under control or establish successful communication, no matter how good our communication is. We had two families who did not trust the team, despite our efforts (...)*, in some cases, they spoke to another doctor to see if we were doing the right thing. In another case, we've noticed evil, somehow perverse behavior, as the family members did not seem to really care about the patient. The team didn't fight back trying to help"* (Health Professional 1).

"There was another very difficult case, in which a mom thought her son would leave the hospital walking. Every day, I would ask her 'how did it go?', then she would explain and I would say 'look, let's talk, it's getting worse, let's give him a pain reliever so he can feel better', but quite often, she refused. You can bring an article, you can talk about other cases, explain and comfort, but there are families that will not (...) *there are the limits of others, it is not easy"* (Health Professional 2).

Even the best communication is subject to certain psychological phenomena that suppress the communicative skills of health professionals. Each individual responds and interprets bad news in an unpredictable way, especially when it comes to life, health, irreversible diagnosis, poor prognosis, and an abrupt change of plans previously established. Strategies can be used to minimize effects, but each one's response will always be unique. Accepting an unfavorable diagnosis depends not only on good communication, but also on the internal resources available to the patient and family members to cope with difficult situations.

When the patient and family members endure suffering due to hostile events, they may deny the current condition as a way to protect their mental integrity. This type of reaction is an important mechanism and reveals the patient's difficulty in accepting the reality imposed. It is not at all related to the way health professionals communicate bad news, but to someone's limit at a given time. Denial is common, and behind this denial is the fear of dying. Under proper professional guidance, patients can gradually absorb the new reality. However, some do not possess the necessary resources for this psychic elaboration of their condition [19].

How to deal with illness depends upon the past of each individual: each experience can be faced as a loss, but also as a chance for transformation and embracing new possibilities. Pain cannot be measured, but what it is and how it hurts says a lot about each person [17]. Even the bond among the health team, patients, and families is permeated by feelings, beliefs, values, fantasies, and subjective expectations, following the transference/countertransference reactions of any relationship. This concept began to be developed by Freud [20] in the early twentieth century and

refers to how one subject projects him/herself onto another with whom he/she maintains a relationship, corresponding to the repetition, in adulthood, of relationships experienced during childhood [19].

In the case of the relationship among the health team, patients, and family members, there are several forms of interaction involved, such as caregiver and patient, who becomes quasi dependent, in many cases; the protective impetus of parents; demonstrations of love; or even situations of abuse of power. Since these relationships involve ambivalent feelings (such as love and hate), it is necessary to distinguish between positive transfer – which implies tender and friendly feelings, and negative, such as hostile feelings (aggression, anger, distrust, rejection).

Occasionally the transference appears to be positive, such as in cases when the patient becomes attached to a health professional, transposing the boundaries of the staff/patient relationship. In such cases, the situation must be carefully managed so as not to negatively influence the therapeutic relationship [19,20]. The health team may also experience feelings toward the patient, the so-called countertransference. These are affective reactions and the subjectivity of the professional projected onto the patient [19,20].

When patients arrive at the hospital, they believe that the health team will minimize their suffering and create hope for the diagnosis. However, it is not always possible to meet their expectations, especially when it comes to palliative treatment with a prognosis that does not predict cure for their disease. Patients may feel overwhelmed, which may cause the dismissal of a health team (negative transfer) that was perceived as unable to help them after all [21].

However, these hostile feelings (anger, professional incompetence) and tender feelings (demand for attention and love) are not personal and not aimed towards the team at all. Instead, they are a subjective content of the patient transferred onto the figure of the caregiver. The feeling of anger is linked to the situation itself, which cannot be changed or reversed [17].

Considering the complexity of this context in a moment of intense pain, tiredness, and grief experienced by patients and health professionals, it is impossible to avoid affective reactions that may very well be impregnated with childhood memories. It is up to health professionals not to internalize these tender and/or hostile feelings, but to identify the transference process, preventing it from influencing the therapeutic relationship. This situation requires professional empathy, professionalism, and personal development. Welcoming patients, being willing to listen to them and understand how they feel help them cope with their problems; signs of aggression, for instance, may be a desperate call for help [6,19].

Implications of the communication established in palliative care during treatment

The literature available and the opinions of the participants have proven that good communication and the relationship established can affect the treatment in many different ways:

"The communication established between the health team and patients is incredibly important for each stage of the treatment, as patient and family awareness greatly improves when they are fully aware of the situation – that is, trust and understanding. When a patient needs to undergo a procedure while awake, I first explain about the procedure, why we are doing it. Explaining minimizes trauma. If patients know what I am going to do, they will feel more relaxed" (Health Professional 1).

"By talking, showing that we have the best interest for her daughter, the mother ends up accepting. So, I think good communication really works and it can really benefit the treatment" (Health Professional 2).

"In the case of a patient who understands, I believe so, if the patient is conscious, he/she is the most interested (...) *in what is going to happen, and not saying anything, not saying good morning, good afternoon, good night. Know what you are doing. For example, someone comes to give me a pill, I will ask what it is for; the health professional has to know, and if they don't know, they have to find out and tell me what the answer is"* (Family Member 2).

The excerpts selected show how dialogue influences the quality of the relationship and the bond of trust to be established between the health team, patients, and family members. As emphasized by Health Professional 1, informing the patient of each phase of their clinical condition and treatment can minimize emotional impact and demystify fantasies, making room for some practical questions instead. Therefore, it is clear that healthy communication restores the dignity and autonomy of patients so they can make decisions about their own lives and treatment, thus preserving self-esteem [22].

For bioethics, empathic dialogue is an essential strategy and skill for the team, who must understand

the anguish and suffering of the patient. At the same time, it promotes beneficence while providing comfort, reducing symptoms, and not causing further harm to the patient, based on the *primum non nocere* principle ("first, do no harm"). Clinical decisions are based on the just deliberation of doing good and not doing harm through prudent approach and constant dialogue; consequently, by establishing bond and trust for consensus among the health team, patients, and family members [23].

Illness causes psychological distress, often accompanied by anguish, fear, and uncertainty. Careful communication helps patients to better understand their illness and the treatment itself, mitigating some of these effects. Given the intense emotional pain, the health team may intervene every so often so that patients and families can absorb the information provided and clarify any doubts, seeking a satisfactory answer to their needs. Adherence to treatment and acceptance of diagnosis and prognosis are influenced by the relationship established and the way professionals conduct communication [24].

This statement also corroborates the speech of Health Professional 2, who emphasizes the importance of respecting how long patients and families take to understand the diagnosis, the poor prognosis, and the care proposed. In addition to mentioning the importance of communication as an important element for treatment, Family Member 2 exposed his perception of a humanized and careful approach aimed towards suffering individuals so they can accept the procedures performed. This interviewee also highlighted the way to greet and acknowledge patients, not seeing them only as an object of medical interventions. Thus, the relevance of the singular referential is resumed, observing what each individual considers essential for good communication; how they perceive the cure; how they control signs and symptoms and follow the guidelines provided by health professionals; the way they deal with disease; and the role of the health team [25].

Finally, the literature emphasizes that managing the transference process correctly, as well as favoring the therapeutic relationship by ensuring the patient's trust and cooperation with the team, is a powerful treatment resource. The health team must remain attentive to the subjectivity and the management of the affective contents (conscious or unconscious) involved in the team-patient relationship can promote positive response towards the drug treatment, the minimization of intense pain, and the improvement of the patient's emotional condition, considering that the placebo effect is associated with the transference relationship with the team [21].

Final considerations

Based on the statements provided by the participants and the theoretical content used, it was evident that adequate communication is essential to promote palliative care, significantly influencing the good relationship between the health team, patients, and family members. However, other aspects (subjective and singular referential, defense mechanisms, transference/countertransference) permeate human relations and suppress the communicative skills of professionals. These are resources of extreme relevance for the work in an environment affected by intense pain and suffering.

Thus, knowledge in bioethics benefits patient care in palliative care, which, as palliative practitioners define very well, is not limited to protocols, but involves principles that infer the reflexive basis of proportionality, reasonableness, and objective good faith that must be present in all clinical decisions, based on deliberative competence and respect for human rights.

Finally, considering that most articles on communication in palliative care are procedural, limiting the subject and the practice of health professionals, there is a need for further studies that address other dimensions of human care, that is, subjectivity, listening, and possible interpretations.

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