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Difficulty communicating the patient's death to family members

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Abstract

Considering that informing family members of a patient's death is an arduous task for health professionals, the objective of this research was to identify in the literature recommendations to reduce the distress caused by this situation. This is a qualitative study carried out by means of a literature review on the Capes Portal database using the terms "death" and "communication." The results, obtained from 18 selected articles, were divided into three categories: professional training, family preparation, and professional practice. Regarding professional training, it was indicated, above all, training by role playing preceded by theoretical foundations; for family members' preparation, the recommendation was to engage in dialogue while the patient is alive; in relation to professional practice, the advice given was information sharing between colleagues and adoption of measures for emotional control. It was found that simulated practices, information sharing between professionals, emotional control of professionals and dialogue with and between family members contribute to reducing the distress when communicating death.

Keywords: Death. Attitude to death. Parental death. Hospital communication systems. Bioethical issues.

Resumo

Dificuldade de comunicar a morte do paciente aos familiares

Considerando que comunicar a morte de paciente a familiares é tarefa difícil para profissionais de saúde, o objetivo desta pesquisa foi identificar na literatura recomendações para reduzir os malefícios dessa situação. Trata-se de estudo qualitativo realizado por meio de revisão bibliográfica nas bases de dados do Portal Capes com a utilização dos termos "morte" e "comunicação". Os resultados, obtidos em 18 artigos selecionados, foram divididos em três categorias: formação profissional, preparo familiar e prática profissional. Quanto à formação profissional, indicou-se, sobretudo, treinamento por *role playing* precedido de fundamentação teórica; para o preparo dos familiares, recomendou-se promover diálogo enquanto o paciente vive; em relação à prática profissional, aconselhou-se compartilhar informações entre colegas e adotar medidas para controle emocional. Constatou-se que práticas simuladas, troca de informações entre profissionais, controle emocional dos profissionais e diálogo com e entre familiares contribuem para reduzir o malefício da comunicação de morte.

Palavras-chave: Morte. Atitude frente à morte. Morte parental. Sistemas de comunicação no hospital. Temas bioéticos.

Resumen

Dificultad para comunicar la muerte del paciente a los familiares

Teniendo en cuenta que comunicar la muerte de un paciente a familiares es tarea difícil para los profesionales de la salud, el objetivo de esta investigación fue identificar en la literatura recomendaciones para reducir los daños de esa situación. Se trata de un estudio cualitativo realizado por medio de revisión bibliográfica en las bases de datos del portal Capes con la utilización de los Términos "muerte" y "comunicación". Los resultados, obtenidos a partir de 18 artículos seleccionados, fueron divididos en tres categorías: formación profesional, preparación familiar y práctica profesional. En cuanto a la formación profesional, se indicó, sobre todo, entrenamiento por *role playing* precedido de fundamentación teórica; para la preparación de los familiares, se recomendó promover el diálogo mientras el paciente vive; en relación con la práctica profesional, se aconsejó compartir informaciones entre compañeros y adoptar medidas de control emocional. Se comprobó que prácticas simuladas, intercambio de informaciones entre profesionales, control emocional de los profesionales y diálogo con y entre familiares contribuyen a reducir el daño de la comunicación de muerte.

Palabras clave: Muerte. Actitud frente a la muerte. Muerte parental. Sistemas de comunicación en hospital. Discusiones bioéticas.

The authors declare no conflict of interest.

Research

Despite being one of the few certainties in life, accepting death is a difficult task, since it is considered an enemy to be incessantly fought and overcome if possible [1]. Therefore, communicating a patient's death to their family is an arduous and delicate task and health professionals, especially physicians, should develop special skills and competences to reduce such impact, which is usually more intense when the event happens unexpectedly.

Among the difficulties, professionals feel a lack of confidence when tasked to reveal the patient's inexorable outcome, fearing that the family may consider them guilty. Likewise, emotional unpreparedness and lack of skills for this type of communication stand out. Thus, considering that the characters of each event have different reactions, this complexity of scenarios demands comprehensive professional training, and there is no predefined speech to face diverse situations [2].

The physician, as the main person responsible for the care, must be very careful about the information to be shared, since it is not enough to communicate death, which is distressing in itself, but they have to express themselves in an appropriate, attentive and careful way, providing comfort to people who are generally unprepared to receive the news. However, it should be noted that even experienced physicians express uncertainty and anguish during communication [2].

The physician-patient bond tends to be deeper in the case of chronic-condition patients, noting that, in the event of death, family members' pain is lessened in an inversely proportional way to the intensity of this relationship. For this reason, it is recommended that bad news be brought by the professional most connected to the patient. Nevertheless, there are physicians, among other professionals, considered insensitive and who, due to lack of humanistic training, do not even speak to the family, sending another professional to give the news [3].

Some communication peculiarities require adequate professional conduct. Thus, when the death of a patient admitted to an intensive care unit is confirmed, for example, communication cannot be given over the phone, and the professional should do it in person.

The more science advances, the more death is feared and denied, and health professionals should have humility and the ability to deal with loss [4]. However, evidence that physicians are not sufficiently prepared for this situation in their training exists; even if having contact with cadavers at the beginning of their studies, they are forced to develop this skill during their professional practice, often without theoretical support [1,5]. Therefore, although physicians acquire some practical knowledge on the subject at work, this lack of foundation should be overcome during their professional training.

The news about death is usually given by the physician, but other health professionals are also involved in this task. Thus, most professional councils have included in their codes of ethics the bioethical principles of beneficence and nonmaleficence as fundamental duties of their members in the fight against human suffering.

The Code of Medical Ethics, in its Fundamental Principle II, guides physicians to act with the utmost zeal for the benefit of human health and, in Principles IV, V, XII and XIII, to avoid harm resulting from: physical suffering, lack of scientific updating of professionals, and failure to adopt preventive measures in relation to occupational or environmental risks [6].

The objective of this study was to identify in the literature the main proposals made to health professionals, especially physicians, to reduce distress caused by the difficult task of communicating the family about a loved one's death.

Method

This is a qualitative study developed by means of a literature review carried out on the Capes Portal database between June and July 2019. For the research, the terms "*communicação* and *morte*" were used to conduct the advanced search in the Portuguese language, and for the search in the English language, the terms "communication and death" only in the title. Due to the limited availability of works in Portuguese language, articles and abstracts from the last 15 years were selected, and for the English language, with a greater availability, publications from the last 10 years.

Research

The study included articles and abstracts with some proposal to guide health professionals on how to communicate a patient's death to family members, with special attention to works with recommendations that can be put into practice. Articles dealing with communication about death in specific cases – such as HIV, pediatric patients and people with disabilities – were excluded because of the peculiarities of characters and contexts involved.

Bardin's content analysis method [7] was used to process the data collected. At the first stage, the pre-analysis was carried out with floating reading, the objective was established and the documents to be analyzed were selected; then, some abstracts related to congresses were included because of the relevance of their proposals; finally, the items selected based on the criteria of relevance and homogeneity of proposals were added.

At the second stage, when the material was explored, the criterion of exclusivity was examined and the proposals found in the works of the three categories were synthesized. At the third stage, which consisted of treating the results based on significance, the proposals were interpreted and the messages inferred and condensed into nuclei of meaning.

Results

Thirty articles were found in the Portuguese language; eight were selected for containing proposals directed to health professionals according to the research objective. The search related to the English language found 119 articles and two abstracts; 34 dealt with the research topic and only ten (eight articles and two abstracts) were selected for the same reason above, but one article was excluded because it was not available.

Thus, 18 articles were included in the study, grouped into three categories – 1) professional training (five articles); 2) family preparation (seven articles), and 3) professional practice (six articles) – according to Charts 1, 2 and 3. The abstracts by Zhang and collaborators [8] and Lambda and collaborators [9] were included because of the importance of their information for the topic related to professional training.

Training of health professionals

Five studies addressed the importance of professional training in communicating death to the patient's relatives and presented proposals (Chart 1). The skills can be acquired via a workshop followed by role playing in small groups, a methodology that was well evaluated among the professionals who participated in the event [10].

Chart 1. Proposals in the category "professional training"

Author(s); date	Proposals for each work	Condensation of proposals
Zhang and collaborators; 2017 [8]	Theoretical course followed by role playing	1. Promote a workshop with role playing 2. Include the content in the bioethics discipline 3. Present didactic videos about death
Lamba and collaborators; 2016 [9]	Presentation of didactic videos followed by role playing, resuscitation maneuvers, and communication about death	
Coyle and collaborators; 2015 [10]	Workshop followed by role playing	
Duarte, Almeida and Popim; 2015 [11]	Approach in the discipline of bioethics	
Kovács; 2011 [12]	Presentation and analysis of didactic films about death	

Similarly, another study pointed out that resident physicians' training through a theoretical course followed by role playing results in increased knowledge of the subject and a feeling of a greater readiness to inform family members of a patient's brain death [8]. A third study with resident physicians adopted the presentation of didactic videos followed by role playing, including cardiorespiratory resuscitation and communication about bad news, providing better emotional control and increased knowledge of the participants [9].

A Brazilian study identified a lack of initiative on the part of educational institutions to offer undergraduate students technical and emotional

skills to deal with death, as described by international studies (Chart 1), which indicate the inclusion of the topic in bioethics teaching as a solution [11].

A final proposal indicated the group analysis of films from the *Falando de Morte* project, which compose a set of films prepared to provide professionals with the skills in communication about death [12]. The five proposals were synthesized and condensed into three, according to the core meaning of their messages (Chart 1).

Family preparation to receive news about death

Seven articles presented proposals on how to prepare family members to receive news about the patient's death (Chart 2). Arranging the meeting between family members and patients when death is imminent facilitates acceptance and contributes to less depression during grief, constituting the first proposal [13].

Conversations between the patient and their loved ones relieves stress and avoids regrets after death, in addition to preparing them for the event, configuring the second proposal [14]. This meeting can be carried out with the help of a program called Death over Dinner (or Death Café), created to stimulate dialogue about death during meetings, an initiative that contributes to the patient accepting their own death, as well as to the family's acceptance, and fits into the third and fourth proposals [15,16].

Chart 2. Proposals in the category "family preparation"

Author(s); date	Proposals	Condensation of proposals
Otani and collaborators; 2017 [13]	Arrange the meeting between the patient and family members before death	
Keeley; 2017 [14]	Encourage the approach to death between the patient and their loved ones	1. Arrange meetings between family members and between them and the patient
South and Elton; 2017 [15]	Organize dinners with family members to talk about death	
Baldwin, 2017 [16]	Organize dinners with family members to talk about death	2. Seek a good relationship between professionals and family members
Jonasson and collaborators; 2011 [17]	Arrange meeting between couples when one is seriously ill	
Starzewski, Rolim and Morrone; 2005 [4]	Good communication and good relationship between professionals and family members	3. Combat social vulnerability
Combinato and Matin; 2017 [18]	Combat social vulnerability	

When no talks about the end of life occur between a patient and their spouse within the three months before death, a greater sense of guilt in the person who lost the partner is felt. Therefore, the fifth proposal is to encourage dialogue about the end of life in couples when a spouse is sick, especially in the terminal phase of life [17].

The sixth proposal is the humanistic and philosophical training of professionals, as well as a good relationship between professionals and the patient's family, favoring communication especially in more difficult cases, such as the death of young people and acute-condition patients [4]. More broadly, the seventh proposal highlights that support for the family can be given through the fight against social vulnerability and measures to reduce social inequalities [18].

The seven proposals were condensed into three, according to the core meaning of their messages, as shown in Chart 2.

Communication about a patient's death: practice of health professionals

Six articles brought proposals on professional practice for communicating a patient's death to family members. As a first proposal, sharing the truth about the patient on the verge of death between the team professionals, without an attitude of denial or concealment, facilitates the process of communication with family members.

This should preferably be done by the physician who is most related to the family and who has the appropriate ethical and technical preparation for the task [19].

The second proposal suggests an increase in the exchange of experiences between an institution's health professionals, as this influences the quality of information transmitted internally, and such sharing improves the information given to family members, leading to fewer avoidance incidences and a decrease in concealment attitudes [20].

According to the third proposal, health professionals must be willing to listen to terminally ill patients to provide them more quality for the rest of their life. Thus, it is recommended that communicating death to the patient and family be done with dedication and trust, providing clear information, in a serene way and in an appropriate place [21].

As a fourth proposal, considering that the physician may express anxiety about their own death and, with this, affect communication and the decisions to be made, attention is recommended to improve their emotional control [22]. As a fifth proposal, it is recommended that the physician should have a life dedicated to the family, with religious practice and hobbies, and that psychological counseling is offered. In addition, the recommendation is to treat the person and not just their disease, an attitude that helps reduce negative psychological effects of medical activity[5].

The last proposal recommends the use of euphemisms by physicians in order to reduce the impact of communication, and the most cited are: "I didn´t succeed," "he/she has already gone," "incompatible with life," "he/she passed away," "he/she did not respond to any of our attempts," "the illness was much stronger than he/she," "the worst happened," "news are not good," "it is better to go than to vegetate," "he/she was suffering a lot" [23].

The six proposals were condensed into four, according to the core meaning of their messages, as shown in Chart 3.

Chart 3. Proposals in the category "professional practice"

Author(s); date	Proposals	Condensation of proposals
Monteiro and collaborators; 2015 [19]	Information shared between professionals and between professionals and family members	1. Information shared between professionals and with family members
Rivolta and collaborators; 2014 [20]	Stimulate information sharing between professionals	
Medeiros and Lustosa; 2011 [21]	The professional must acquire communication skills and be willing to listen	2. Developing skills in professionals
Drapper and collaborators; 2019 [22]	Control of the professional's anxiety and feelings	3. Promoting a balanced lifestyle and psychological support for professionals
Tamada and collaborators; 2017 [5]	To have emotional balance, the professional should have a balanced lifestyle and psychological support	
Souza and collaborators; 2018 [23]	Use of euphemisms such as: "I didn't succeed," "he/she has already gone," "he/she was suffering a lot," etc.	4. Using euphemisms can help some professionals regarding communication

Discussion

In the three categories analyzed (Charts 1, 2 and 3), the articles presented 10 relevant proposals to health professionals, especially physicians, regarding the difficult task of communicating a patient's death to their family members. Regarding professional training (Chart 1), in three of the five selected articles and abstracts [8-10] the first proposal appears – role playing –, preceded by a theoretical introduction through expository presentations or didactic films. Therefore, it is inferred that this is the most suitable methodology for the development of professionals' skills and emotional during communication about death.

This methodology can use simulated patients or only students playing the roles of physician and

patient. In a literature review, it was also indicated as the most recommended for acquiring skills in breaking bad news to patients in case of unfavorable diagnoses, which is an analogous situation [24].

Recent research found that medical students consider the acquisition of new humanistic skills in their training important to improve physician-patient, physician-interdisciplinary, physician-disciplinary and physician-family relationships (with a social view of the patient). These qualities contribute to improving the team's performance and its members' emotional control in the face of more complex situations in the profession, such as the communication about death [25].

Still in the category "professional training," two more proposals appear regarding the acquisition of the ability to communicate death: 1) it can be included as part of the bioethics discipline, or 2) it can be studied from the presentation of educational videos on the topic [11,12]. These are alternatives from works developed in Brazil, possibly because most Brazilian schools still do not provide the role playing method for acquiring communication skills. However, no studies clarifying this situation in the country were found.

In bioethics teaching, this theme is included in the tenor of the principle of nonmaleficence. Presenting didactic videos during training provides the opportunity to access theoretical knowledge that can be developed during professional practice.

Regarding family preparation (Chart 2), three proposals were presented and the main one affirms that talking about death is the best way to prepare them for the event and, consequently, reduce grief distress. In this context, couples need to talk to each other before one of the spouses' death, as well as family members of patients in the terminal phase of life, in order to reduce their own pain during grief [13,14,17]. In this situation, each family member experiences different emotions and, when people share experiences, they get closer to each other, facilitating the acceptance of death and reducing mourning time.

The second proposal of this category recommends a good relationship between professionals and patients; however, the authors highlight the lack of humanitarian and philosophical training of professionals [4]. Chapter V of the Code of Medical Ethics deals with the relationship with patients and family members, which considers it a physician's duty [6]. For professionals, as there is no ready-made speech that facilitates communication in all possible cases, broad and continuous training with the acquisition of skills that allow them to be prepared to give adequate answers in each situation is required [2].

Finally, the third proposal, which is caring for social vulnerability to reduce family member's pain and can occur mainly via assistance in the various difficulties surrounding death [18]. Death is normally a rare event in a family, and many difficulties and doubts can arise from the lack of knowledge, from obtaining the death certificate to the place destined for the funeral and burial. Therefore, in addition to communication skills, professionals need to have the willingness and knowledge to help with the practical aspects that follow the family member's death.

Regarding "professional practice" (Chart 3), four proposals were presented, with highlight for the first, according to which sharing information about the patient's conditions or their death among team members contributes to the avoidance of uncertainties with the family caused by possible contradictions [19]. It is very unpleasant for family members to receive mismatched information, which only increases the anguish of such a difficult time; therefore, the multidisciplinary team must talk to each other. The information should also be transmitted calmly, with clear words and in an appropriate place [4].

As a second proposition, it is recommended that professionals have a constant willingness to develop communication skills and direct the focus of their attention on the patient rather than on the disease [21]. This approach values the humanitarian action of professionals and helps remove the feeling of defeat in the face of imminent death – although situations that are more difficult and require greater skill and emotional balance exist, such as the communication about the death of acute-condition and young patients [4]. The Code of Medical Ethics, in its Fundamental Principle V, recommends constant professional improvement to physicians, which includes communication skills [6].

The third proposition recommends the family members' good emotional preparation. Thus, although the manifestation of empathy by the health professional who communicates death helps

to alleviate family suffering, the psychologist's action can be relevant to improve the relationship between professionals, patient and family [26]. Health professionals can improve their emotional control by undertaking courses, lectures or discussion groups, but informal conversations and personal therapy to achieve this important objective are also important [27].

During professional training, practices that contribute to the development of emotional competences can be included, since some factors negatively influence the interaction, such as bad relationships with colleagues or leadership and inadequate infrastructure during night shifts, considered more stressful [28]. In the proposal by Silva, Cordeiro and Lima [29], a pedagogical intervention aimed at the comprehensive training of medical students would strengthen the development of socio-emotional skills and, consequently, improve their human development.

In this sense, to avoid professional frustration, the recommendation is that during the medicine undergraduate course the approach to death should be less biological, especially removing some of the importance of cure as the sole objective of treatment [30]. In teaching hospitals, where the emotional burden is usually high, the implementation of a specialized service with psychological support programs for health professionals is suggested for better stress control [31]. Recommendations also include a systematic assessment of the professionals' mental health, and the existence of a multidisciplinary team to support individual work and relieve stress [32].

The fourth proposition consists of using euphemisms, which, although can be criticized for allowing misinterpretations, are used by many professionals to soften the difficult information to be given, making the words not as unpleasant for family members. Many euphemisms were pointed out by Souza and collaborators [23], such as "I did not succeed," "he/she has already gone," or "he/she was suffering a lot," among others (Chart 3).

Using euphemisms during conversations between oncologists and family members and end-of-life patients is quite common, and explicit answers (direct and without euphemisms) occur mainly in the case of a direct question [33]. In order for the health professional, especially physicians, to become more confident, it is recommended to teach protocols for breaking bad news during the undergraduate course, such as the SPIKES protocol, which was highly accepted by students of a medical course [36].

Final considerations

The proposals to reduce distress when communicating the patient's death to family members appeared in the three categories analyzed.

Regarding "professional training," it is proposed that health professionals acquire skills via meetings that begin with theoretical classes and are complemented with role playing as the main training strategy. The approach to the topic as part of the bioethics discipline or through the use of didactic videos was pointed out as an alternative methodology.

Regarding "family preparation," good communication between health professionals and the family, stimulus to dialogue about death among family members before the loved one's death, and the fight against social vulnerability are propositions that aim at greater coherence and solidarity.

In relation to "professional practice," information sharing, acquisition of communication skills and development of emotional control through specific support programs are recommended, as well as the adoption of a balanced lifestyle. Use of euphemisms to reduce the negative impact of communication is not left behind; however, care should be taken so that the practice does not result in omission of the truth.

To respect the principle of nonmaleficence – one of bioethics' fundamental precepts and one of the oldest in medicine – good intentions alone are not enough. Thus, a training process on comprehensive communication is necessary, which includes emotional balance, adoption of humanistic practices and acquisition of technical knowledge and specialized skills.

A limitation of this study was the reduced availability of studies carried out in Brazil on role playing, a methodology frequently proposed in international studies, used during the undergraduate course to develop skills in communicating a patient's death.

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Research

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