

The ethical dilemma of breaking bad news in palliative care

Introduction

In palliative medicine, it is easy to get into a situation where there is uncertainty about how best to proceed in providing medical and supportive care. What is good, in the sense of good for the patient, is an ethical question. The tools of medical ethics help to find ethically acceptable practices, legal standards and medical guidelines, which then provide a framework within which to seek ethical acceptability.

Communicating bad news about life-threatening and possibly incurable conditions is an important part of the practice of physicians and pediatric care in this situation. Physicians are instructed on how to communicate bad news to patients and their families. Communication of bad news is defined as conversations between physicians and parents regarding their child's serious diagnosis, limited treatment options, or poor prognosis. Many health professionals feel uncomfortable when breaking bad news and little is known about how patients and parents of children with life-threatening conditions experience breaking bad news.

This topic is very close to my heart because, in addition to working as a physiotherapist, I also provide care and counseling to families of children with muscular dystrophy. Palliative care is provided to these children in full and we often see poor communication between health professionals and families.

1 Communication of a serious diagnosis from the doctor's point of view

Delivering bad news is one of the hardest challenges that a doctor faces in their medical practice (Sobczak et al., 2018). This is an extremely burdensome situation for both parties involved, i.e. for the one who communicates the diagnosis and for the one to whom it concerns. There is no universal guide on how to proceed. The information that a person is seriously or even terminally ill is a shock for the patient. And how do parents feel when they find out that their child has an incurable disease (Kutnohorská, 2016)?

The information communicated by physician should be based on the patient's current health conditions. Physician has to ask himself the following questions: What to say, how to tell, when to tell, to whom to communicate (or not to communicate)? The patient's good should be the priority when deciding (Ivanová, 2018). Can physicians deliver bad news? Are they prepared for these situations?

The fears doctors have about delivering bad news include being blamed, evoking a reaction, expressing emotion, not knowing all the answers, fear of the unknown and untaught, and personal fear of illness and death. This can lead physicians to become emotionally disengaged from their patients (Monden et al., 2016).

When physicians lack proper training, breaking bad news can lead to negative consequences for patients, families, and physicians. Monden et al. (2016) used a questionnaire to

determine whether a didactic program on delivering bad news was needed at their institution. Results revealed that 91% of respondents perceived delivering bad news as a very important skill, but only 40% felt they had the training to effectively deliver such news.

Sobczak et al. (2018) states throughout his research that the opinions and feelings of patients about the way the bad news was delivered to them is medically important. The behavior of doctors and the manner of their delivery bad news is decisive for further results of therapy. The behavior of the doctors and the delivery method are bad news influences patient's decisions to discontinue or continue their medical treatment. It also affects the patient's decision making about changing their responsible doctor or about continuing their activities medical therapy under the guidance of a doctor who had provided the diagnosis.

Even in the Czech Republic, there is still no mandatory training for future physicians in the field of palliative medicine and communication with terminally ill patients and their families.

Thus, physicians can only learn communication procedures on their own initiative. For example, our Palliative Care Center offers workshops led by doctor Adam Houska. This is based on the American SPIKES recommended procedure, which includes six steps (see below).

There are a number of best practices that are good to follow when communicating important news so that both parties feel as comfortable as possible in the situation.

Monden et al. (2016) in his article he summarizes the results of several authors. The best training will embrace a patient-centered approach that includes the patient's family. The physician conveys the information according to the patient's and patient's family's needs. Identifying these needs takes into account the cultural, spiritual, and religious beliefs and practices of the family. It has also been shown to yield the highest patient satisfaction and results in the physician being perceived as emotional, available, expressive of hope, and not dominant.

The authors agree that the best training should additionally include a protocol for delivering bad news. Several protocols have been proposed and tested in the literature.

Fine (1991) proposed a protocol with five phases. Phase 1) preparation, involves establishing appropriate space, communicating time limitations, being sensitive to patient needs, being sensitive to cultural and religious values, and being specific about the goal. Phase 2) information acquisition, includes asking what the patient knows, how much the patient wants to know, and what the patient believes about his or her condition. Phase 3) information sharing, entails reevaluating the agenda and teaching. Phase 4) information reception, allows for assessing the information reception, clarifying any miscommunication, and handling disagreements courteously, while phase 5) response, includes identifying and acknowledging the patient's response to the information and closing the interview.

Baile et al. (2000) proposed a protocol called SPIKES: S – setting up the interview, P – assessing the patient's perception, I – obtaining the patient's invitation; K, giving knowledge and information to the patient, E – addressing the patient's emotions with empathic responses and S – strategy and summary.

Authors Rabow and McPhee (1999) also proposed a model for delivering bad news called ABCDE: A – advance preparation, B – build a therapeutic environment/relationship, C – communicate well, D – deal with patient and family reactions, and E – encourage and validate emotions.

The authors also agree on other factors that are important for the communication of bad news and should not be neglected. Specifically, the environment, the place should be quiet, comfortable and private. Regarding the conditions for conducting the interview, bad news should be communicated at a time that is convenient for the patient, without interruptions, with sufficient advance notice and in person. Ideally, those receiving the bad news should have the choice of being accompanied by someone close to them. When it comes to delivering the message, clinicians should be prepared, find out what the patient already knows, convey a degree of hope, allow for emotional expression and questions, and summarize the discussion. The message should be conveyed with empathy, respect and in language that is understandable to the patient, free of medical jargon and technical terminology (Monden et al., 2018; Baile et al., 2000).

2 Communicating a serious diagnosis from the perspective of the patient and parents of ill children

Dutch author Marije Brouwer et al. (2020), conducted a comparative analysis in the form of in-depth interviews with parents who have or have had a child with a life-threatening condition. This study shows healthcare professionals how parents experience barriers in bad news conversations.

Based on parents' experiences, the following 10 barriers to the communication of bad news were identified: 1) a lack of (timely) communication, 2) physicians' failure to ask parents for input, 3) parents feel unprepared during and after the conversation, 4) a lack of clarity about future treatment, 5) physicians' failure to voice uncertainties, 6) physicians' failure to schedule follow-up conversations, 7) presence of too many or unknown healthcare professionals, 8) parental concerns in breaking bad news to children, 9) managing indications of bad news in non-conversational contexts, and 10) parents' misunderstanding of medical terminology (Brouwer et al., 2020).

Similar information is summarised in research in Poland by Sobczak et al. (2018). Patients who had a bad experience of being told bad news about their health state reported the following as inadequate: 1) the doctor's behaviour at the time of the bad news, 2) the amount of time spent on the visit, 3) the doctor's lack of attention, 4) the use of medical terminology, 5) the doctor's honesty, and 6) the doctor's emotional and cognitive support.

After analyzing patients' specific responses, they concluded that in their opinion, physicians are more effective when it comes to conveying technical information related to their medical knowledge, but have difficulty with expressive communication based on empathy and accurate recognition of others' feelings, emotional states, and emotional needs (Sobczak et al., 2018).

No scientific research has been published in the Czech Republic that includes the experiences of patients and parents in communicating bad news about their health or their children's health. However, from the media and from my own experience, the experiences are very similar to those reported in the previous two cited researches. According to Adam Housek, a doctor from the Centre for Palliative Care, who was interviewed for a radio broadcast in December this year, the situation in the Czech Republic is similar. Parents realise the fatality of the diagnosis of their dying children on average three months later than doctors, often due to mismanaged communication between doctors and parents of young patients. The most common mistakes include a lack of privacy during the conversation, getting bogged down in medical terminology or a physical barrier on the table between the doctor and the parents: for example, an open laptop that the doctor slides his eyes to when the situation makes him uncomfortable. On the other hand, he states that when a serious situation is first communicated, it makes no sense to give rational information; patients and parents are in shock and highly emotional. At that moment, it is necessary to focus on these emotions and respond to them empathically in some way. Lucie Hrdličková, a doctor from the Department of Paediatric Haematology and Oncology at Motol Hospital, adds that the way a doctor conveys information has a great influence on how parents will cooperate with doctors in the future and to what extent they will suffer from psychological problems. According to parents' experience, in the first moment after the bad news is communicated, in shock they do not perceive at all what the doctor communicates, but only in what way (Trachtová, 2022).

The previous text looked at the situation in three European countries where we have similar health care, culture and religion, and the results of studies and available information are very similar. But what is the situation outside Europe, specifically in India and Africa?

Das (2021) and his team published a study in India that summarizes the experiences of parents of dying children and their doctors. The study was conducted in the pediatric ward of a tertiary care hospital in Delhi, based on in-depth interviews with parents and family members. Doctors were the main communicators. Most of the parents perceived the approach, communication and language used by the resident doctors as terse, insensitive and sometimes inappropriate or negative. They perceived the approach and communication of the lead physician as empathetic, positive, and complete. Most parents did not receive any emotional support from health care providers during and after their child's death. All doctors expressed that their patients' deaths affected them and their emotions, which they coped with through various activities. Overcrowded wards, high workload, infrastructure limitations, and no formal communication training contributed to the emotional stress of health care providers. The authors conclude by suggesting physician training in communication and the adoption of a specific communication protocol as a starting point to improve the quality of care (Das et al., 2021).

Research in rural South Africa, where palliative care in children has not been provided for as long as elsewhere in the world, has highlighted different experiences of palliative care providers in children than in previously commented studies. The authors identified four dilemmas that they addressed.

1) children's families do not want to be told bad news, 2) some palliative care providers do not want to tell bad news, 3) some palliative care providers want to tell bad news, and 4) palliative care providers do not know when to tell bad news. The study therefore confirms that in rural South Africa people have many different customs related to dying, death and grief. These customs differ from those in other parts of the world and it is recognised that culture and indigenous knowledge systems are important factors in the delivery of health care (Campbell et Amin, 2013).

3 Legal norms in ethics

Disclosure of information to the patient is currently one of the ethical and legal issues in our healthcare system. Not only in the Czech Republic, but in all countries, the most debated topic is how to communicate information to a terminally ill patient with an unfavourable prognosis. Ethics addresses this problem as an ethical dilemma: Truth or lie at the hospital bedside (Bužgová, 2013)?

3.1 Communicating health information

The main legal norms in the Czech Republic related to this topic are the Convention on Human Rights and Biomedicine and Act No. 372/2011 Sb. on Health Services. According to the first mentioned legal norm, everyone has the right to know all information about his/her health condition, but only if he/she wishes to do so, except for minors and incapacitated persons. In exceptional cases, the doctor may decide otherwise in the interests of the patient. The second standard states the obligation to inform the patient of his/her state of health to a sufficient extent, in a comprehensible manner and about the various treatments. Allowing the patient to ask questions about his/her health and treatment, to refuse to provide information about his/her health or to determine to whom the information will be provided. In the case of minors and incapacitated persons, the right to information is given to the legal guardian and the patient if he/she is of sound mind (Bužgová, 2013).

3.2 Communication of information about an unfavourable diagnosis

Doctors have long been concerned with the question of whether or not to disclose the truth about a patient's medical condition. The ethical dilemma speaks to the truth at the hospital bedside. There is simply no clear-cut procedure. What is good for the patient, whether true or false, is not always judged equally. Bužgová (2013) states that a lie is only excusable if people expect and count on it. However, the truth at the hospital bedside is not just about the doctor, it is related to the ethics of dying and therefore concerns the patient who should be fully informed about their condition. The truth can reassure, encourage and liberate the patient. On the other hand, it raises many questions that need to be answered. The doctor should have sufficient time to answer all the patient's questions and then, taking into account the patient's wishes, inform other persons, such as family members, etc., taking into account legal standards.

Conclusion

Communicating bad news is certainly very difficult for all physicians and non-physicians. It always depends on the individual doctor and the individual patient. Certainly the setting, the timing, when and what to communicate is important. Comply with legal standards while maintaining the ethics of the medical profession. The starting point should be that all staff working in palliative medicine should be trained for situations involving the communication of bad news, both to patients and with regard to their own person. To do this, they need to develop their own attitude towards death and dying and to accept death as part of human life.

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