

	<p>XIV. Study unit: Psychotherapeutic steps in the communication of bad news</p> <p>Imola Sándor, György Purebl, János Pilling</p>
Aim	<p>The aim of this chapter is to acquaint the students with the communicational techniques applicable in the imparting of bad news.</p>
Introduction	<p>Introduction</p> <p>In this chapter you will become acquainted with the simpler communication and psychotherapeutic techniques, by which the news, arising during medical work, which is usually upsetting and emotionally burdensome for patients, can more efficiently be communicated. (These are usually illnesses that influence the future prospects of the patient permanently, fatal illnesses or ones that entail some kind of deficiency, amputation, communicating the news of someone's death etc.) Efficient communication is important not only for the reduction of the emotional burden of the patient, the relative and the doctor, but for the sake of the maintenance of compliance too.</p> <p>Target group: general practitioners and medical students</p>
Important	<p>Suggested study methods:</p> <p>Read the texts and the case illustrations. Following this, answer the comprehension questions. If you were not able to answer all the questions, survey the problematic parts in the texts again, and finally do the self-check tests.</p> <p>We suggest that the study material should be surveyed in one go. Total amount of study-time necessary: 6 hours</p>
Important	<p>Recommended literature</p> <p>Fallowfield L, Jenkins V (2004). Communicating sad, bad, and difficult news in medicine. Lancet 363: 312-319</p>
Summary	<p>Content of chapter:</p> <p>XIV./1. The notion of bad news. Communicational models of the imparting of bad news</p> <ul style="list-style-type: none">XIV./1.1 ConcealmentXIV./1.2 The model of communicating everythingXIV./1.3 The model of individual information <p>XIV./2 Practical steps of the communication of bad news</p> <ul style="list-style-type: none">XIV./2.1 The circumstances of the communication of bad newsXIV./ 2.2 The process of the imparting of bad news<ul style="list-style-type: none">XIV./2.2.1 PreparationXIV./ 2.2.2 Opening questionsXIV./2.2.3 Asking for consentXIV./2.2.4 Information about the illness

	<div>XIV./2.2.5 Supportive behaviour</div> <div>XIV./2.2.6 Summary</div> <div>XIV./2.3 The duties of the doctor after the conversation</div> <div>XIV./2.4 The handling of difficult questions</div>
Important	<div><div><i>XIV./1: The notion of bad news: communicational models for the imparting of bad news</i></div><div>Introduction</div><div><p>In the curing work we call bad news every such piece of information which negatively influences the patients’ future prospects to a significant degree. Consequently, bad news may be the explanation of the diagnosis of a chronic disease, or the communication of the impairment/loss of a body function, some permanent health damage, amputating surgery, congenital deformity, but also the imparting the news of fatal illnesses or death.</p><p>As for the communication of bad news, numerous medical attitudes may be observed, on the basis of which many different communicational models have been employed in the various health care systems. The medical personnel often put the question of “shall we tell or shall we not” into the centre, in spite of the fact that on the basis of the antecedents (the nature of complaints and examinations) the majority of patients usually do expect bad news.</p><p><i>The World Health Organisation has found the following three approaches in the communication of bad news:</i></p><div><div>1. The concealment of the nature of the illness, of bad news</div><div>2. The immediate and comprehensive information of the patient (the model of prompt, full disclosure)</div><div>3. Information tailored to the needs of the patient, which is disclosed gradually, and in several steps (the model of gradual disclosure)</div></div><div>XIV./1.1 Concealment</div><div><p>In earlier days the model of concealing the diagnosis was a widespread practice in Hungary too.</p><p><i>The diagnosis was generally imparted to the relatives. This model is disquieting for several reasons:</i></p><div><div>▪ The majority of patients want to know what is happening to them;</div></div></div></div></div>

- Everyone has a right to the information concerning his own person;
- Patients are usually not spared emotionally by the concealment of bad news, moreover, it may bring further negative feelings to the surface: patients, on the one hand, already suspect what is happening to them, for they deduce it from the nature of the therapy and the examinations (and from the aggravation of their condition), but often they draw inferences from the non-verbal communication of the medical personnel. Since they are not informed frankly, their uncertainty concerning the situation increases, and they are compelled to utilize other sources of information, which weakens the doctor-patient relationship, and there is the danger that they judge their situation more negatively than justifiable.
- Family members are compelled to assume an air of secrecy, which burdens the patient-relative relationship, and this is particularly harmful in a situation when the overt and honest communication within the family may be a very important resource of energy for the patient

Beyond all these, the application of the model of concealment is not authorized by the prevailing Hungarian provisions of law.

XIV./1.2 The model of communicating everything

According to the model of communicating everything, patients must be informed of bad news immediately and comprehensively. Although this model is apparently in complete conformity with the rights of patients regarding information, in practice, however, this model may not be applied in all cases.

- It is a right but not a duty of the patient to know the information pertaining to him, thus he may ask not to be informed
- Patients need time for processing bad news. For the patient to be able to efficiently interpret and accept the news, the information must, in many cases, be measured out gradually, in accordance with the psychological endurance of the patient.

XIV./1.3 The model of individually tailored information

According to the model of the individually tailored information patients are different, thus they require personally tailored communication – particularly in emotionally burdened situations. The essence of the model is that the doctor informs the patient according to the actual needs of the patient, thus often the information is given in parts in the course of several meetings and not in one go.

Advantages of the method:

- It takes the personality, education, knowledge, actual state of mind and endurance of the patient into consideration
- It puts the least possible emotional burden on patients and relatives
- The patient himself determines how much and what kind of information should he be given by the doctor at a given meeting

	<ul style="list-style-type: none"> ▪ The patient has enough time to psychologically process the bad news ▪ It is more likely that he will be able to cope with the situation and mobilize resources from his environment ▪ Compliance is most successful with the application of this model ▪ There are no concealed facts, communication remains open among doctor, patient and relatives, thus therapy and the management of practical issues is more easily realizable ▪ This is the model that fits the Hungarian legal regulations and clinical practice best
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Important	<p><i>XIV./2.: Practical steps in communicating bad news</i></p> <p>In the following we are going to show the way of imparting bad news according to the model of individually tailored information.</p> <p>XIV./2.1. The circumstances of communicating bad news</p> <p>Bad news has to be imparted by the patient's medical professional face to face. Bad news must not be imparted on the telephone for legal and practical reasons.</p> <p>If the patient has more than one medical professional (in the case of comorbid illnesses), bad news has to be imparted by the one, who acquires the information first. Should the doctor redirect the patient, he has to inform the doctor of the receiving institution what he has concretely informed the patient about.</p> <p>Bad news has to be disclosed to the patient himself. It is worth asking the patient whether we should inform one of his relatives as well – informing a relative may be done only with the permission of the patient. We also have to ask the patient concretely what we are allowed to tell his relative.</p> <p>If the patient arrives escorted by his relatives, we have to ask his permission for his relatives to remain during the conversation.</p> <p>We have to provide a convenient place (consulting room) and time for the conversation.</p> <p>XIV./ 2.2. The process of communicating of bad news</p> <p>The imparting of bad news is a process. Communicating bad news may only be based on certainty, in the case of a well-grounded suspicion, however, when the examinations are already specifically aimed at the confirmation of the presumed diagnosis, we may, conditionally, raise the suspicion of a malignant disease in the following way:</p>
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Summary

1. **We explain what the examination is specifically aimed at** (*“We’d like to dissect a little piece from the deformation which can be seen on the X-ray, so that we may perform a biopsy”*).
2. **We tell the patient about our suspicions regarding the disease.** We should speak in the conditional mood, and should try to delineate as many alternatives as possible. In the case of a tumour we should emphasize the preclusive – rather than the confirmative – function of the diagnosis (*“This deformation may be several things: some remnant of an old scar, an inflammatory focus, but with this examination we can preclude the likelihood of benign and malignant tumours as well.”*)
3. **We tell the patient why is it specifically necessary to perform this examination** (*“The dissected piece of tissue can be directly observed with a microscope, and several other examinations may also be performed on it.”*)

In the case of certainty, we proceed according to the steps of the SPIKES model (Setting up the interview, assessing the patient’s Perception, obtaining the patient’s Invitation, giving Knowledge and information to the patient, addressing the patient’s emotions with Empathic responses, strategy and Summary).

XIV./2.2.1 Preparation (Setting up the interview)

In this stage we prepare for the conversation (“inner wash-up”). For this we should provide a suitable place, and an adequate amount of time (we should minimize our phone accessibility too, as much as possible). Let’s arrange some water, a glass, some tissue paper! Let’s ask the patient whether he would like one of his relatives to be also present during the conversation.

Think it over in advance what exactly we would like to talk about with the patient:

- How do we build up the communication of bad news (see in the following)
- What further treatments do we suggest to him?
- What other possibilities can we offer him (patient organisations and civil supporting organisations)
- What written supporting materials can we give or recommend to the patient (patient information leaflets, brochures of patient organisations, self-help books and homepages – this latter one is particularly important, for the majority of patients gather information from the Internet anyway, but do not always prefer information which is valuable also from a medical point of view).

XIV./2.2.2 Opening questions (assessing the patient’s perception)

The purpose of the opening questions:

- it establishes the process of the communication of bad news
- it reveals the patient’s preliminary knowledge, presumptions, beliefs
- it throws light on the expectations of the patient
- and on his psychological condition

Types of opening questions:

Important	<ul style="list-style-type: none"> ▪ How do you feel? ▪ Has anything changed regarding your complaints lately? ▪ What have other doctors and other members of the medical profession have told him so far? ▪ On the basis of his knowledge and experiences so far what does he currently think of his illness? – We tell him that for us it is a very important piece of information, because he is the one, who knows himself (and his own body) the best, and he is the one who is going through this situation. <p>The opening questions help to chart how much information the patients have about their condition, how they assess it, how much they are aware of the gravity of the illness and of its possibly fatal outcome.</p> <p><i>XIV./2.2.3 Asking for consent (obtaining the patient's wishes)</i></p> <p>In this stage we ask the patient how much he wishes to know about his illness, since he has the right to be informed, but he may not necessarily want to be informed at the current time. That is, we should ask the following:</p> <ul style="list-style-type: none"> ▪ <i>“There are patients who would like to be told everything, and others who are interested only in the main points. What would you prefer?”</i> ▪ <i>“Would you like me to give you a detailed account of everything right now, or you would prefer to be told the relevant details at each and every step of the examination process?”</i>
Connection	<p><i>XIV./2.2.4 Information about the illness (giving knowledge and information to the patient)</i></p> <p><i>Aspects of communicating information:</i></p> <ol style="list-style-type: none"> 1. Unambiguousness and to-the-point communication. This situation constitutes tension for the doctor himself, and many try to dissolve it by lengthy explanations, paltering or by speaking “in the language of flowers”. All of this only further increase tension and may lead to the misunderstanding of information, and have a disturbing effect on the patients, who are usually interested in the key facts. 2. Gradual disclosure and continuous two-way communication. Information is portioned out gradually, step by step, in accordance with the psychological endurance of the patient. Recommended steps in alphabetical order: <ul style="list-style-type: none"> A. <i>“Unfortunately the results are not as good as we had expected.”</i> B. <i>“I’m sorry to say, but the histology shows a malignant tumour.”</i> <p>We pause, and watch the reaction of the patient. If he is listening, we can go on, but if he has something to say or sinks into himself, this constitutes an informational block (that is, the patient is currently not receptive to any new piece of information), so we should either listen to what he has to say, or wait for a little while</p>

C. *“I’m sorry to say, but this tumour is of a malignant kind.”* We pause again, and watch the patient’s reaction. We should let the patient ask questions, we may even encourage him to do so, and involve him in conversation.

It is important to communicate sincerely, but it does not necessarily mean, we have to tell everything immediately. For this reason it is worth encouraging the patient in the second stage of our conversation to put questions, so that we may proceed along them:

We may also use figures, emphasizing, of course, the chance of survival: *“If the illness is discovered in this stage, then, according to statistical data, 45% of patients survive the 5 years subsequent to the diagnosis.”* In case the patient is able to face the situation psychologically, he understands that the risk of dying is high. If not, he may cling to the 45% chance of survival. We have told the truth to the patient, and let him choose, which piece of information he clings to.

The process of communicating bad news is not a single time occasion, but may be drawn out to many occasions.

3. It is very important to try **to avoid the so-called semantic confusion**. This means that the patient and the doctor understand certain words differently. A good example for this is the word *tumour*: in medical thinking this is not necessarily negative, since there exist several benign tumours and curable malignant tumours as well. In the lay persons’ usage, however, the word tumour has a much more negative meaning, and many automatically mean the malignant tumour by it. Thus it is important to elucidate who means what by certain words and expressions, and it is advisable to avoid ambiguous designations.

XIV./2.2.5 Supportive behaviour (addressing the patient’s emotions with empathic responses)

The essence of supportive behaviour is that we are continuously considering the patient’s reactions. The process of communicating information has to be accompanied by support all the way through. In the course of the conversation, as we have already mentioned above, information blocks may evolve, when the patient is unable to receive new information, he may ask apparently inadequate questions, but intense emotional reactions (e.g. crying, fury, anger) or, on the contrary, an emotionally paralysed state may also come about on hearing the bad news. In these moments we may use several empathic communicational techniques for the emotional support of the patient and for pushing the conversation on.

They can be such, as: acceptance, empathic reflections, supportive silence:

“I see I’ve upset you very much by what I’ve told you.”

“I see this is very difficult for you now.”

For the assessment of the patient’s current psychological condition and for pushing the conversation on we may also use questions:

“May I ask you what are you thinking of now?” (in case of silence)

“At the time you noticed your complaints, did you think that an illness like this may’ve been in their background?”

During the resumption of the conversation we should strive to highlight the

positive elements and emphasize the things we can do for the patient and those we cannot. Possibilities should be repeated several times, because this way there is a greater chance of the patient's clinging to these during the conversation and not focusing onto the possible losses. It is often the case that despite all the above mentioned communication techniques we cannot have the patient – during the first meeting –concentrate on the possibilities, since he is traumatized. This is why there often need to be further consultations..

What communicational phrases should be avoided?

“Please, don't cry, pull yourself together” – crying is an important emotion regulatory behaviour, and traumatized persons cannot pull themselves together.

“I'm very sorry that I have to say this, but...” – in this case we should rather avoid using the word “but”, the narrative function of which is the annulment of the first clause. It is enough for us to say: *“I am very sorry, and I'll try to do all I can to help you in this situation.”*

“I know what you feel now” – this we can never know for sure, and patients in this situation feel that no-one can understand them. It is better to reflect what we see of the patient's behaviour, e.g.: *“I see that it is very difficult for you now”*,

“Don't worry, everything's going to be all right” – This kind of communication, which is meant to be a reassurance, usually elicits an inverse effect. Instead we suggest saying: *“We'll try to give you all possible help.”*

XIV./2.2.6 Summary (strategy and summary)

In this stage it is very important to discuss what further steps are to be taken. .

1. Discuss with the patient what further things are there to be done, and pay regard to the needs of patients as much as possible.
2. Call the attention of the patient to the expected emotional reactions (torment, anger, crying, sudden fits of passionate emotions), and assure him that these are natural.
3. Help the patient in making the most of social support. Ask him to think over who those persons are he can count on in this situation, and who can help in what. Call his attention to the civil (if there are any) and professional (e.g. a supporting nurse within an oncological workgroup) support possibilities. We should recommend homepages for reading. A significant number of patients seek further information on the Internet, inadequate information, however, may confuse them – that is why we should recommend them homepages ourselves.
4. At the end of the conversation we check how much he has understood of what we have talked about. *“Has there been anything, which might have been less understandable for you?”* or *“What has been the most important for you from this conversation?”*
5. We should end the consultation only after having fixed the date of our next meeting.

XIV./2.3 The handling of difficult questions

In the course of the conversation patients may spring several such questions and

Task

Read the supplement.

statements on the doctor that are very difficult to respond to.

A few examples:

“Then I’m going to die?”
“Is there any point in the treatments at all?”
“So I have to go through a lot of suffering with these treatments, and in the end I’ll die anyway...”
“How can one live with one leg, in your opinion?”
“How will I look into the eyes of my wife...?”
“You cannot understand this...”
“You cannot help me”

The common feature of all these is that they are categorical and several emotions and thoughts may stand in the background, and patients are primarily expecting answers. Thus these are the things which should be clarified first.

1. **Clearing up the background of a “difficult sentence”** through empathic questions instead of immediate responses. In the following we are trying to give a few examples:
 - “You’re asking this because you are afraid that your illness cannot be cured?”
 - “You’re asking this because you don’t really trust the treatments?”
 - “Which, do you think, are the greatest difficulties regarding this?”
 - “Are you afraid of the reaction of your wife? How, do you think, your wife might react?”
 - “You’re wondering whether you can trust me and the treatment.”
2. **We should refer back to our earlier talks.** “Perhaps you remember that yesterday we were talking about the prospective benefits of the treatment.”
3. **We should be honest and supportive at the same time.** *“This is a dangerous illness indeed, but we’ll do everything for the sake of your recovery.”*

“This illness cannot be cured, but by medicinal treatment we are striving to do everything for the improvement of the quality of your life.”
4. **We should admit what we don’t know.** In the case of an uncertain prognosis we should admit that we don’t know what direction his illness takes, nevertheless we should assure the patient of our support. We should point out that every patient is a unique case, and much depends on the patient’s own efforts. If there are statistical data at our disposal, we should use these, always emphasizing the recovery rate. “65% of patients with this illness come through it.” On account of all these we should never tell an exact period of time for the survival (we cannot, anyway)! For the explicit question of the patient (“How much more time do I have, doctor?”) we should give an answer defined in months and years, or perhaps in a broader interval, but never in exact numbers (e.g. instead of *5 months*, we should say *a few months, half a year, perhaps more*), and we should always point out that a lot depends on the patient’s own efforts!
5. **We should keep up hope!** In a terminal state this certainly cannot pertain

to survival, for we always have to tell the truth. Patients, however, do not necessarily seek hope in this (they may hope they do not have to face greater pain, or that their relationship with their relatives remains undisturbed, etc.). We should ask the patient what he needs, and try to help him in this.

XIV./2.4 The duties of the doctor after the conversation

The doctor has to document who were present at the conversation, what was said about the illness, the prognosis and about further diagnostic and therapeutic steps, how the patient (and his relative) reacted, what further steps have been agreed upon, and when the next meeting will take place.

Later, the members of the attending workgroup need to be informed about the conversation, so they also will be fully aware of what stage the patient is in concerning the reception of bad news, and also of the extent of the information.

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