Chapter 5 Communication in Palliative Care

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Introduction

Good communication skills are obviously important for any health professional, but they are especially essential when taking care of patients facing a life-threatening disease. It is never easy to give news about a diagnosis and/or prognosis that will give patients a perspective of death far closer than imagined. Not only are these communication skills important when breaking news initially and through patient follow-up, but such skills also allow effective collaboration with other involved health professionals. In the palliative context, these skills do not only facilitate the proper management of physical symptoms, but also assist in other dimensions, such as social, spiritual, and psychological, which all must be addressed. The patient remains, of course, at the center of care with involvement of family/loved ones, but each member of the healthcare team has specific competencies that must be acknowledged and shared.

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N. Vadivelu et al. (eds.), *Essentials of Palliative Care*, DOI 10.1007/978-1-4614-5164-8_5, © Springer Science+Business Media New York 2013 In addition, distressed, exhausted family members may sometimes be difficult to manage. Family caregivers may show dysfunction, aggressiveness, or denial, but their needs also must be addressed as these behaviors may be signs of intense suffering. Finally, it is important to ensure that the needs of a "difficult" family do not bring team members to exhaustion. This, also, is the role of a coordinated, communicative team approach.

In complex medical situations, the patient usually receives care not only by the primary care provider, but also by several specialists, sometimes in various locations. If healthcare providers involved in the patient's care fail to coordinate their efforts, patients and their family members may hear several "stories" regarding the patient's present and future condition, which may be distressing or confusing. Implementing a smooth transition and a relation of trust between the patient, family, and healthcare providers can be achieved only if there is real collaboration/communication between these healthcare providers, with understanding of the roles of each professional involved.

Breaking bad news is not an easy task and will never be, whatever our professional training, experience, or level of empathy. Some individuals may have natural communication skills, but one can always improve. Students and professionals from various disciplines (physicians, nurses, medical school and nursing school students, psychologists, social workers, chaplains) may learn how to better communicate at any stage of their career. Observing skilled communicators is a good way to learn, but observation will never take the place of "hands-on" training. Working with standardized patients or role playing may promote improvement without the fear of "hurting" a patient; thus, training in a formal, resourced environment is optimal. Several communication skills training programs have been described in the medical literature and have proven to be highly effective, including training models for medical students [1, 2]and for oncologists [3, 4]. One Cochrane review confirmed that several training models, both those for physicians and for nurses, appear to be effective [5].

We will mainly focus on a very important aspect of communication in palliative care: Breaking bad news. We will also explore briefly issues that are of special interest too in this area: dealing with "difficult" families and communicating with other health professionals.

Breaking Bad News

Throughout time, there has been an evolution from Hippocrates' recommendation (late fifth century BC) [6]: "Conceal most things from the patient while you are attending to him. Give necessary orders with cheerfulness and serenity...revealing nothing of the patient's future or present condition. For many patients ... have taken a turn for the worse ... by forecast of what is to come" and those from the American Medical Association in the nineteenth century [7]: "The life of a sick person can be

shortened not only by the acts, but also by the words or the manner of a physician. It is, therefore, a sacred duty to guard him carefully in this respect and to avoid all things which have a tendency to discourage the patient and to depress his spirits." Closer to us, in the 1960s, when oncological options were still scarce, physicians tended to consider it inhumane to break bad news to a patient while knowing that there would be no treatment option to offer [8]. Today, however, finds a tremendous emphasis on the patient's autonomy and right to know everything about his or her condition and to make his or her own decisions. Physicians also face the challenge of tailoring the delivery of bad news, depending on the assessment of the specific patient's wishes, needs, culture, and resources.

"I left my house on October 2, 1996, as one person, and came home another" [9]: this quote from Lance Armstrong after being informed of his advanced oncological condition illustrates how stressful and life-changing receiving bad news is.

Four key points need to be considered while delivering bad news:

- 1. Address the patient first, even if the patient appears confused or unwilling to participate. If comatose, never talk to the family as if the patient were not present. The patient must remain the center of care in all circumstances [10]
- 2. Ask the patient, if able to communicate, if and how the family/loved ones should be involved in the discussion, to emphasize the right to privacy if desired [10]
- 3. Demonstrate that you and all the healthcare providers involved are going to team with the patient and the patient's caregivers/loved ones in this difficult period. Fine et al. demonstrated that even though the first thing that the patient requests is good symptom management, "companionship," which means an active "partnership" not only with his family members but with the healthcare providers too, is very high in the list of needs [11]
- 4. Do you need to get more involved in the patient's decision-making process? This is a rather provocative concept as today's Western societies emphasize patient-centered decision making and the concept of autonomy. Nevertheless, patients may prefer their doctors to be partners and may sometimes ask physicians to take difficult decisions for them. A recent study conducted by Chungon more than 8,000 hospitalized patients showed that even though 97% of respondents wanted doctors to offer them choices and to consider their opinion, two out of three preferred however to leave medical decisions to their physician [12]

Several guidelines on the sequence to follow when delivering bad news have been published, some of which being available in a convenient format, which are worth having in the lab coat pocket for a quick double-check before a meeting, especially at the beginning of training. Some are based on simple mnemonic (*ABCDE*) [6],on steps [13, 14]or acronyms (SPIKES) [15, 16]. All account for the important elements of a good discussion not only while breaking bad news, but also while discussing other important issues, such as advanced care planning or treatment goals. One of these guidelines, SPIKES, was also assessed as an education tool for the ED residents to ease the discussions with the family members after a patient's death [17].

Table 5.1 Checklist of key elements for a successful meeting while breaking bad news

Getting ready for the meeting

- Determine who will be present (a)
- Obtain/review all necessary information regarding the patient's condition and plan of care *before* the meeting
- Discuss briefly with the professionals who will be present, what the main point(s) to discuss are, who will lead, and who will answer questions of various topics
- · Determine the amount of time necessary to dedicate to the meeting
- · Prepare an appropriate environment
- Minimize distractions from cell phones, pagers, disruptions. Ensure that every medical team member is physically and mentally prepared

Initiating the meeting

- Be on time
- Introduce everybody; be sure that everybody is sitting comfortably
- The meeting leader will set up the timing and explain the goal of the meeting, and suggest some "rules" (e.g., only one person speaks at a time, with no interruptions)

During the meeting

- Start by addressing the patient: "Mr. X, how are you feeling now?"
- Briefly assess patient understanding: "What do you know about your situation?" (b)
- Assess patient readiness for receiving the bad news, and the level of detail necessary to provide: "What do **you** want to know" (c)
- Break the news (d)
- Respond to emotion (e)
- Be attentive (especially to the patient and the family reactions, nonverbal language, and interactions)
- Plan the follow up (f)

After the meeting

- Create a written summary of the meeting, including date, participants' names, decisions, problems, plan of care, and specific elements of meeting
- · Determine if the team achieved its initial goals
- Assess what went well and what did not
- Determine who is going to perform necessary follow-up tasks
- Reflect on your own and the team members' limits (e.g., bad personal period, fatigue, feelings of medical team members toward patients and patient family members) (g)
- Assess availability and access to our resources (h)

Table 5.1 presents a series of the main elements to consider in order to facilitate communication when bad news is to be presented. Additional information regarding some of these key points are detailed afterwards.

(a) Determine who will be present

It is important to determine how many family members are expected or are key persons, and which team members' presence would be helpful. It is better to be accompanied by another member of the healthcare team, especially if not experienced, not knowing the situation well, or feeling uncomfortable or unready. The patient needs to know that his or her physician will not neglect treatable aspects of health, diabetes, hypertension, nutritional deficiencies, etc. There is no shame in asking for help! Do not hesitate to send reminders of the meeting and to request a confirmation from the participants, especially if you will meet several key family members.

(b) Briefly assess patient understanding

Some possible questions

- "Could you describe your medical situation for me in your own words?"
- "When you first had this symptom, what did you think it might be?"
- "Are you worried about your illness or symptoms?"
- "What did my colleague (oncologist, PCP, radiologist...) tell you about your condition or the procedure you underwent?"

In a study conducted by Rowland Morin, it has been shown that some of the factors of satisfaction of the patients during initial interviews with physicians was their use of silence or the reaction time latency between speakers [18]. As it has been demonstrated that most patients take two minutes to answer your questions, but that an average medical doctor interrupts the patient within 18–23 s, so hold on!

This important step may allow you to understand:

- What the patient knows ("I have lung cancer, and I need surgery")
- What he understands about his disease ("the doctor said something about a spot on my chest x-ray")
- His level of technical sophistication ("I've got a T2N0 adenocarcinoma")
- His emotional state ("I've been so worried I might have cancer that I haven't slept for a week")
- His relations with his family members ("Let me talk for a change, I'm the sick one")
- (c) Assess patient readiness for receiving the bad news, and the level of detail necessary to give

Some possible questions:

- "If this condition turns out to be something serious, would you want to know?"
- "Do you want me to go over the test results now and to explain exactly what they mean?"
- "Some patients want me to cover every medical detail, but other patients want only the big picture. What would you prefer now?"
- "Some persons prefer not to be told what is wrong with them, but would rather have their family told instead. Both solutions are perfectly OK. What do you prefer?"

(d) Break the news

The topics you would like/need to cover during the meeting may be extensive and address the diagnosis, potential additional investigations, treatment options, prognosis, and/or advanced directives.

It is very important to:

- Use softening language as you begin to prepare for the delivery of bad news.
 You may say: "I feel badly to have to tell you this," "I'm afraid the news is not good," "The report is back, and it is not what we hoped for."
- Talk in a sensitive but straightforward manner.
- Avoid the single, steady monologue. Give pieces of information in small chunks and pause frequently ("I'm going to stop for one minute to see if you have some question at this point.").
- Avoid technical jargon (no pathophysiology course) or euphemisms (the "mass," the "problem").
- Check for understanding. ("You just received news that is not what you expected. There is a lot going on right now for you and your family. Please tell me if you understood everything I told you or if you want me to go back to some specific issues.").
- (e) Respond to emotion:
 - Be ready to face a broad range of reactions (e.g., denial, blame, intellectualization, disbelief, acceptance, anger).
 - Wait and be there. Silence and the use of nonverbal language are great tools that we underuse.
 - Have tissue papers available.
 - Acknowledge the emotions.
 - "I'm sorry" and "I don't know" are OK!
 - Avoid defensiveness regarding the medical care. Do not criticize other healthcare professionals.
 - If things turn bad and you face an aggressive reaction, do not take it personally and do not respond in the same way.
- (f) Plan the follow-up:
 - Give additional information on potential treatments options, further necessary investigations, and appropriate referrals. ("We'll go step-by-step.").
 - Maintain realistic hope. "There is nothing we can do for you" is the worst thing we can tell our patients from an emotional standpoint, in addition to being completely wrong. Palliative/EOL care has much to offer regarding symptom management and can address the various dimensions specific to the patient.
 - Allow extra time for final questions (while respecting the time allocated). Help break the news to the family if no member is present during the meeting.
 - Never leave the patient without having organized a follow-up appointment or a phone call contact. Reiterate that you will be there to help in difficult moments.
 - Always double check: Is the patient alone? Driving? Depressive? Suicidal? Living alone? Does he have former or current addictions?
 - Organize, if needed, prompt social, psychological, and/or spiritual support.
 - If the patient has been admitted, try to avoid holding the discussion at the time of discharge. The patient may need the supportive environment of the hospital to make his or her initial accommodations.

(g) Reflect on your own and the team members' limits:

Breaking bad news may be challenging and may bring us above our limits. We can experience a sense of failure and frustration with the inability to help more or by judging our performance while breaking the news. Some professionals may even desire to avoid a specific patient and family to escape these feelings. These feelings can be exacerbated if we have simultaneously developed a close relation and start to identify with the patient (e.g., patient who looks like our own father, young patient with children the same age than ours, etc.), undergo a difficult personal period, or are overwhelmed by a huge work load. These emotions may affect both the patient's care and our well-being. Such unexamined emotions may lead to disengagement, poor judgment, distress, and burnout [19]. It is said that approximately one of every three physicians will experience burnout at any given time, which could lead in the worst cases to substance abuse, intent to leave medical practice, and suicide [20]. Even though a recent review failed to demonstrate that burnout levels were higher in palliative care health workers than in other contexts [21], we may imagine that in this specific context with a constant immersion in a field where patients of all ages present very advanced conditions, the risk of being overwhelmed may be higher than in other medical areas. For this reason teamwork is so important. A health professional should not be the only one to carry the weight of this difficult moment. Discussing with colleagues after the meeting about what was said, what happened in the meeting, the plans for patient care, and making plans to share responsibilities can be tremendously helpful.

(h) Access to our availabilities and resources

Also, it is important to make sure that you have personal resources and to know that you can access them. For some of us, it is just our family circle, for others, such resources can include extreme sports, nature, arts, meditation, or any of a number of other sources of coping. Whatever it is, we need to know what can help us. Seeking professional help can also be an asset in difficult moments. There is no shame to request help from our peers, from our mentors, or from professionals. Remember that if you arrive in the stage of burn-out, you will not only hurt yourself, but you will not be of any help to your patients and your team!

Other Important Issues

"Doc, how much time do I still have?" Physicians are not good prognosticators. A 2000 study conducted by Christakis et al. asked 343 doctors to provide survival estimates for 468 terminally ill patients (<6 months to live if disease ran expected course). For this population, which finally had a median survival of 24 days, 63% of the physicians were overoptimistic, and 17% overly pessimistic, a long relationship with the patient being associated with overestimation [22]. Over-optimism as well as unnecessary pessimism may harm, it may be wise to remain vague at the beginning and to reassess on a regular basis rather than to cite a bunch of statistics. If a specific

patient requests statistics, it is important while giving them to emphasize that each patient is unique, and that it is almost impossible to predict where in these statistics the particular patient will fall.

"To touch or not to touch?" We are often concerned about being disrespectful of the patient's private sphere if we touch his hand or his shoulder. Usually, patients with oncological situations, especially ones presenting with mutilating lesions, may feel rejected and find comfort in being touched. Holding a patient's hand may also give you important clues: Is the patient cold? Shaking? Myoclonic? If the patient does not find comfort in being touched, the patient will tell you, either directly, or through nonverbal signs.

What Does the Patient Remember?

Several studies have shown that the patient may not remember points physicians addressed. In a recent study, Olson et al. interviewed patients on their discharge day. Among the patients, only 57% knew their present diagnosis while 77% of the physicians were sure that they were aware of it [23]. Even more relevant, when a new medication had been prescribed, 20% of the patients said their physician never told them about it, while all the physicians said they had told them about it. Regarding the side effects, only 10% of the patients said they were told about them while 81% of the physicians said they had described them. This discrepancy is probably even more present when the patient has to assimilate bad news.

The Importance of the Body Language

Four components are important:

- The first impression: Shake hand, make eye contact, be seated
- The physician's nonverbal language
- The patient's nonverbal language
- The family members' nonverbal language

The first two components will help you create a good relation with your patient and family members. These elements should be addressed in any communication training. The last ones will bring you invaluable elements which may help you to obtain a global vision necessary to build up a strategy of care.

Cultural and Spiritual Issues

As society becomes more pluralistic, physicians will face increasing numbers of patients from various cultures or religious backgrounds. The more we know about

the different needs of diverse patient groups, the more tools we will have to deal appropriately with situations involving them. Studies have shown that people from many different cultures are more likely to believe discussing death can bring death closer, including Native Americans and immigrants from Africa, China, Korea, and Mexico [24]. Even though patient autonomy is a strong cultural value in the USA and other Western cultures, it is not the same in some non-Western cultures, such as those found in Asia and Latin America, where primary decision makers are often supposed to be the family members. The more we know about these different visions, and the more we respect them as well as their spiritual beliefs, the more it will help build a relation of trust between the patients and us. It is often rewarding for the patients and their families when physicians ask questions about their culture and their beliefs. It is also always possible to contact a spiritual leader or an influential member of a specific community to obtain as much relevant information as possible—all within the requisite of patient confidentiality and trust.

Communicating with "Difficult" Families

Integrating families and loved ones in patient care is a mandatory part of good palliative medicine as defined by the most recent WHO definition [25]. The patient needs to know that we take care of the needs of loved ones, too, and that these loved ones can be part of the decision-making and care process if the patient so wishes. Also, it is often extremely difficult for patients to know they are leaving behind beloved ones after death, and the patient sometimes worries more about them than about him or herself. For this reason special emphasis is placed on end-of-life family conferences. Several guidelines have been developed to help organize these conferences [26, 27].

It can likewise be extremely difficult for family members to see their beloved one decline and sometimes suffer or be confused. Family members may feel guilty because they cannot help the patient more. Often, these family members are themselves on the verge of exhaustion. Sometimes family members and loved ones are left in terrible distress, and for this reason bereavement services are offered as part of regular hospice care for up to 13 months following the patient's death.

Relationships physicians develop with the patient's family members and loved ones are often excellent, rewarding, and helpful. The longer physicians interact with these caregivers and the more the family trusts the physician, the better this relation may become. Especially effective physicians consistently emphasize the important role family members play in their beloved one's care, gather family members' opinions on this care, and allow them to ask any question they may have [10]. It is also important to ask family members on a regular basis how they are feeling and coping with this terrible situation. It may be useful for the physician to acknowledge that this caring may be a physical and emotional drain on family caregivers. Proactively suggesting "respite" may relieve guilt and promote better relationships between the patient and the family caregivers as well as between the family and the physician. In some occasions however, the communication with the family may be more challenging than the patient's care himself, whether the patient is still able or not to communicate accurately. Some family members may express their suffering in various ways that can be difficult for the healthcare providers to handle. This may be the family members' way trying to deal with a reality they find intolerable. Physicians must understand that unpleasant reactions may only be the expression of an intense suffering. Family members may be extremely demanding, come back again and again with unrealistic expectations and hopes, interfere with best care practices ("no morphine, I don't want him to receive dangerous medications," even while the patient is in excruciating pain or severe dyspnea), or sometimes be very aggressive and question the physician's every suggestion. Healthcare professionals may also face the occasional pathologic personality among family members, such as narcissistic, antisocial, or other personality disorders. Some family members may also present with active addictions that will also interfere with the patient's care.

If the patient's family members had very disappointing interactions previously with other healthcare providers, sometimes believing that the patient has been not diagnosed on time, or did not receive the care they would have desired, they may not be quickly willing to trust any doctor again, and the medical team may need more time and a united effort to gain their trust again.

Past or ongoing conflicts among family members are sometimes exacerbated in the end-of-life period. Some family members, who may not have been present and involved in the patient's care previously, may feel a form of guilt and aggressively manifest these feelings by trying to exert control in the situation, which may upset other family members. There may also be financial concerns or interests. And family members may inappropriately expect members of the healthcare team to determine who is right or wrong, which may put physicians and others into difficult situations [27].

Some important points:

- 1. If a scheduled family meeting is expected to be difficult, it is important to prepare the meeting carefully. Make sure that all the main family members will be present and ask them confirm their presence. Prepare a team approach and have all the relevant team members available before starting the meeting. If you expect six family members, try not to be alone; show a coherent interdisciplinary approach. On the other hand, with one or two family members only, having them to face a whole healthcare team may be overwhelming.
- 2. Try to figure out as soon as possible who holds the patient's power of attorney, whether there is a living will if the patient is not able to communicate, and determine clearly who will be the main contact among the family members.
- 3. Be especially clear in your expectations during this meeting. Difficult family members often lead to difficult meetings. Expectations regarding meeting time, how the meeting is led, as well as ground rules on participation—that all members participate in turn and that shouting, cursing, and violent behavior are not accepted. When situations are expected to be particularly tense, be sure to have prompt access to security. If you see that you do not have any more control of the situation, and the discussion arrives at a dead end, it is better to call for a "time-out" and to reschedule another meeting.

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- 4. No member of the healthcare team should be recruited to judge family conflicts. Likewise, family conflicts should not be mirrored by healthcare team members. Dysfunctional family members may be highly skilled at recruiting others into their orbit and thus splitting the healthcare team. In some occasions, it is worth asking an angry person to address you rather than another member of the family to avoid a spiral of discord or violence.
- 5. Before the meeting, try to gather as much information regarding the specific cultural and spiritual context of the present family as possible. Showing your knowledge, your interest and, most importantly, your respect for other cultures and religions may help improve communication and create trust relations with the family members [28].
- 6. As usually, remember that it is always better to ask for help if needed: a more experienced colleague, a palliative care physician, or an ethics committee consultation may be of help.
- 7. After the meeting, take time to debrief the situation within the team. Document all possible elements, the family and team members present, what was discussed and the decisions taken. Do not forget that there is always a risk of lawsuit, particularly when family members are angry, excessively distressed, or otherwise highly emotional.

Communication Among Health Professionals

Patients and their loved ones with advanced disease face numerous, well-documented problems—the poor prognosis, symptom burden, and suffering, as well as the logistical difficulties of a heavy schedule of appointments, sometimes in various locations, with conflicted schedules, heavy costs, and long waiting times—but such difficulties are only exacerbated when the patient and his loved ones receive conflicted opinions from various healthcare professionals. It is especially difficult if one professional questions openly the attitude of another one.

Another difficult situation when the patient switches abruptly from a primary care provider to a specialist like an oncologist, and the switch can be even more distressing when going from the specialist from whom he expected potential cure to palliative or hospice care.

In these terrible moments when the patient faces death, the patient needs even greater trust in the healthcare providers, and to know that they will work all together to offer the best option appropriate to the specific situation, adjusting to changes in the disease state and goals of care. If we go back to Fine's survey conducted among hospice patients and asking the simple question: "What would be the most useful way I can be of help to you today?", symptoms relief came first of course, but close to this came the request of companionship [11].

It is also well represented in this African proverb quoted by Spruyt: "If you want to travel quickly, go alone. But if you want to travel far, you must go together" [29].

In fact, there is a lot to do in the travel toward death in a palliative condition, and the way is sometimes long. We need to join our efforts to help our patient and the patient's loved ones to go through this travel as smoothly as possible. We need to collaborate and communicate better, whether among team members, or the various physicians involved.

Interdisciplinary Team Communication

A well-conducted hospice team meeting is a wonderful example of the effectiveness of interdisciplinarity. Medical students or young residents who attend these meetings for the first time are very often surprised to see that the physician is not the "leader" of the team. Each team member, physician, nurse, psychologist, social worker, chaplain, pharmacist, volunteer, is important, as each of them has a specific expertise and unique skills and values that work in synergy with those of the other team members. We know the importance of close communication, respect, shared team philosophy, as well as good interpersonal relationships among the team members if we want to offer the best care to our patient [30].

Communication Among Physicians

This is as important as the interdisciplinary communication. It is not rare at the hospital to have a patient assessed by several specialists, sometimes giving contradictory opinions regarding treatment options or global attitudes, without discussing with their colleagues, leaving the patient feeling powerless and confused. The first question at any moment should always be: "Who will take the decisions and organize the care offered to the patient." This "captain" should obtain information from all the specialists and organize the plan of care accordingly. Regular meetings among all involved specialists are ideal of course, but due to the busy schedule of all the physicians such meetings are difficult to coordinate sometimes. The communication between the primary care physician, the specialists, and then the palliative care or hospice physician must be maintained to avoid the patient distressing transitions. It is also a good way to gather new information, to have a better idea of the "reality of the other," and to demonstrate our respect for our colleagues. Finally, the technology that surrounds us is wonderful, but sometimes a simple phone call or a visit to a colleague will be more helpful and personalized that the most sophisticated electronic letter.

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Review Questions

- 1. In a global population discharged from the hospital, how many patients can tell you their current diagnosis?
 - (a) 90%
 - (b) 75%
 - (c) 57%
 - (d) 35%
- 2. For how long does a "standard" physician let a patient talk before interrupting him?
 - (a) 18–23 s
 - (b) 30–60 s
 - (c) 2–3 min
 - (d) Usually does not interrupt him
- 3. When you have to break bad news to a patient, what is one of the most important initial step?
 - (a) To be sure that you will have time to address all the important issues, such as diagnosis, prognosis, treatment, advanced directives
 - (b) To find somebody willing to do this for you
 - (c) To discuss in the corridor, standing, to avoid to spend too much time with the patient
 - (d) To try to have all the relevant information available
- 4. Is Palliative Care a medical specialty with higher risk of burn-out than others?
 - (a) Yes
 - (b) No, it is ICU
 - (c) No, it is surgery
 - (d) No, the risk is the same in all medical specialties
- 5. The best way to improve your communication skills is:
 - (a) There is no way to improve, either you are an innate good communicator, or you are not
 - (b) To observe skilled colleagues or mentors
 - (c) To learn from our mistakes
 - (d) To follow a formal communication training

Answers

- 1. (c) 57%
- 2. (a) 18-23 s
- 3. (d) To try to have all the relevant information available
- 4. (d) No, the risk is the same in all medical specialties
- 5. (d) To follow a formal communication training