

METHODS OF COMMUNICATION BETWEEN THE MEDICAL STAFF AND THE FAMILY OF THE DECEASED CHILD

CĂLIN LAZĂR¹, VIOREL LUPU², DANIEL DAVID³, ELENA PREDESCU²,
 BIANCA ANDREICA², ROXANA SIPOS², SEMPRONIA FILIPOF²,
 RODICA MANASIA¹, IOANA MARIN-CĂRPINEANU², LINDA SALESKI⁴,
 ROBERT SHAPIRO⁴, J.S. THOMPSON⁵

¹Department of Paediatrics I, "Iuliu Hațieganu" UMPH, Cluj-Napoca

²Department of Paediatric Psychiatry, "Iuliu Hațieganu" UMPH, Cluj-Napoca

³Department of Clinical Psychology and Psychotherapy, "Babeș Bolyai" University of Cluj-Napoca

⁴St. Anthony Hospital, Oklahoma City, USA

⁵Oklahoma University Health Science Centre, Department of Radiation Oncology, Oklahoma City, USA

Abstract

Acquiring communication techniques with the patient/the family in extreme medical situations (incurable disease, death) represents an important gap in medical education. The article focuses on: a. Stages of parent crisis at the moment of their child's death; b. Practical details about communication (choosing the right moment, ensuring privacy, speech and gesture, active listening from the part of the doctor); c. Communication in case of sudden death occurring in the Emergency Department; d. Most common mistakes made by medical doctors (MD) when releasing such news. Having adapted the data provided by bibliographical sources the authors have conceived the Good Practice Guidelines. This article also tackles issues generated by stress in the medical workers involved in such situations by addressing the causes of professional burn-out, its occurrence and ways of mitigating the phenomenon. The authors reiterate the importance of professional training for MDs in this respect and the need for dedicated university courses in cycle II or post-graduate studies. In a medical era dominated by technology, improving communication between the MD and the patient and their families becomes a top priority given that communication is highly important especially in critical situations.

Keywords: attitude to death, bereavement, professional burn-out.

METODE DE COMUNICARE ÎNTRE PERSONALUL MEDICAL ȘI FAMILIA COPILULUI DECEDAT

Rezumat

Deprinderea tehnicilor de comunicare cu pacientul/familia în situații medicale extreme (boală incurabilă, deces) reprezintă o lacună importantă a învățământului medical. Articolul analizează: a. Stadiile crizei prin care trec părinții în momentul decesului copilului lor; b. Detalii practice ale comunicării (alegerea momentului, asigurarea intimității, mesajul verbal și gestual, ascultarea activă din partea medicului); c. Particularități ale comunicării în caz de moarte subită în Unitatea de Primire a Urgențelor; d. Cele mai frecvente greșeli ale medicilor la anunțarea unei astfel de vești. Adaptând datele oferite de resursele bibliografice existente în alte țări, autorii au conceput un ghid de bună practică care poate reprezenta un instrument util medicului aflat în aceste situații extreme. Articolul dezbate și problemele generate de stress-ul personalului medical implicat în aceste situații, prezentând cauzele, modul de manifestare și posibilitățile de atenuare ale fenomenului de "burn-out". Autorii

reiterează importanța training-ului în acest domeniu al medicilor și necesitatea introducerii de cursuri universitare în ciclul II de pregătire sau cursuri post-universitare. Într-o eră medicală dominată de tehnologie, se impune ameliorarea comunicării dintre medic și pacient/familia acestuia, aspect de o deosebită importanță mai ales în situații critice cum este cea abordată în prezentul articol.

Cuvinte-cheie: atitudine în fața morții, pierdere ireparabilă, stress profesional.

For the pediatrician one of the most traumatizing experiences is the death of a patient. The feeling of being helpless and useless, the feeling that maybe you would have managed to save his/her life if you had administered different treatment or if you had just “seen” the diagnosis earlier – all these are amplified by the effort to find the right words when you have to deliver the dreadful news to the parents.

On the other hand there are the parents, victims of an emotional trauma. The grief of losing one’s child cannot be compared to any other psychological grief: “A wife who loses her husband is called a widow. A child who loses his/her parents is called an orphan. There is no word for the parent who loses his/her child, so painful this loss is!” [1].

Stages of the Crisis Undergone by Parents When Their Child Dies

The psychological analysis of the parent crisis in such moments showed 4 progressive stages according to Kübler-Ross model of psychological grief perception [2,3]:

1. *Initial impact:* prevalence of shock estate and denial to accept reality (“what is happening to me cannot be real”); these reflex mechanisms protect parents from a much too painful reality; when they are told the news, they do not pay attention (they look out of the window or they look at their watch), they are paralyzed with fear or take automatic actions (robotic movements, sometimes pointless).

2. *Realization:* a wide range of reactions, from immobile face to quiet crying or a crisis of hysteria; nondirectional anger or anger targeted at the medical staff occurs frequently; in some situations (suicidal or unintentional poisoning, road accidents) the parents’ self blame might occur; depending on their religious denomination, some parents perceive such events as divine punishment, with traces of resignation (“this is God’s will”).

3. *Defensive retreat:* a stage dominated by depression; many a time parents avoid the reality which is introduced to them by trying to cling with their minds to the period before the tragedy (“It’s only a bad dream, isn’t it?”).

4. *Acknowledgement:* final stage in which parents accept reality.

Informing Parents of the Death of Their Child

On making the announcement, the MD has to convey three fundamental feelings [4,5]:

1. *Regret:* “I feel very sorry that you have to face this grievance”.

2. *Acknowledging the importance of the loss suffered:* “I realize that for you this is a very hard test”.

3. *Reassuring commitment:* “I am here for you, please let me help you”.

During this difficult process, the MD must pay attention to both verbal and non-verbal communication [6,7,8].

Preparing communication. The MD is encouraged to note down beforehand all information that he/she wants to deliver in order to be prepared and to have the right message and the appropriate tone. **Choosing the moment.** The moment for communicating the tragic news must not be delayed. Keeping the family in uncertainty leads parents towards false hopes.

Ensuring privacy: Conversation will take place in a setting that ensures a minimum standard of privacy. Triggering a wide range of reactions (of which some violent) in front of other children or parents makes the latter feel increasingly insecure and fosters entropy within the department. For such moments it is preferred enter an isolated room, with no disturbing factors (radio, TV etc.) and mobile phones and pagers shall be turned off during the communication process. It is advisable that the MD allocates enough time for the communication and that he/she does not leave the room until the family have exhausted all the questions. Should the MD be called for an emergency with another patient, he/she shall ensure the members of the family of the fact that he/she will be back with them as soon as possible, and in this time span it is advisable that a different member of the team stays with the family members

Type of verbal message: The MD shall try to gather all the family in one place (allowing for family members to interactively support one another) and communicate the news only once in order to avoid being exposed to extreme psychological exhaustion for several times in a row. The verbal message has to be clear, honest, concise and straight forward. MDs shall use the word “death” and

avoid a number of euphemisms (“has passed away”, “did not respond to treatment” etc.) which are too ambiguous for parents in emotional shock. MDs shall adapt the language to the intellectual level of the parents, as well as to the low level of understanding of people in such moments. Formal expressions are frowned upon (“he/she deceased”) as these may induce the feeling that the MD is inappropriately distant. Medical data shall be briefly provided, without using super-specialized language or medical jargon. Too much information can be overwhelming and some doctors feel like filling the silent moments with excessive scientific data.

Non-verbal communication: It is recommended that the MD sits down near the parents or even face to face. The MD shall not avoid eye contact with the parents and he/she shall not take inappropriate stands (such as sitting on one corner of the office desk, arms crossed or legs crossed) that may induce the feeling of detachment and indifference. There is nothing wrong in touching the hands of a grieving parent or embracing him/her.

Active listening: The MD needs to be a good listener and – very important – not to rush. Parents shall be encouraged to speak without being interrupted in the middle of the sentence and all short moments of silence shall be respected.

Track record of notes referring to communication: It is very important to confirm in writing, through documents, the communication process and the reaction of the patient/family and to mention any witness to the discussion. Such recordings may prove useful should a medical malpractice complaint occur.

In these critical moments the doctor should show empathy and compassion. The boundary between compassion and intimacy is set by each MD according to his/her own emotional capacity. False compassion or stating compassion in an exaggerated manner may raise suspicions from the part of the family (“is this doctor blaming himself/herself for something?”). The way in which the MD communicates the news of the death is essential so that families perceive the message in the right way and further show emotional feedback [9,10].

Due to the insufficient training in communication during critical moments, the MD often adopts wrong attitudes and adds even more grievance to the immense suffering of the parents. Studies have identified the most frequent mistakes made by MDs in such extreme situations [11,12]:

1. Starting the discussion without being prepared emotionally and psychologically to answer any question (the lack of answers or ambiguous answers may raise suspicions about possible medical mistakes).
2. Choosing the wrong place for communication and not ensuring privacy for the moment.
3. Communicating separately with the parents.
4. Too distant an attitude as against the tragedy of

the bereaved family.

5. Not granting enough time or leaving the room suddenly after delivering the news.
6. Using medical jargon.

Death of a Child in the Emergency Department.

The death of a child in the Emergency Department raises a number of specific problems [13,14,15]:

1. The organization and design of this department makes it difficult to ensure privacy. In most the Emergency Departments there are no special rooms for such a discussion with the parents.

2. In comparison to other departments, in most of the cases there is no previous connection with the family and this impairs communication. In a very short time the MD has to realize what is the level of education and the capacity of understanding medical terminology to which he/she must adapt her/his speech, as well as the adequate emotional level for discussion.

3. The dynamic character of the Emergency Department does not allow for family compassion and support. Because of the high case flow and busy schedule, the medical staff grant too little time to such an important discussion. Although the MD is the person to announce the death, there are authors who suggest that specialized teams (including psychologists, medical assistants, social workers, priests) should take part in the emotional support offered to the family [16,17]. These teams can help parents understand the type of medical care the child benefited from and explain to them what to expect when they are due to see the lifeless body of the child. A study from 2008 [14] enquired 40 parents whose children died in the Emergency Department about the way in which they were told about the death of their child. The most frequent answer pointed at the lack of availability and attention paid to the family’s need to receive information. Other aspects recorded by the study include: incomprehensible information, too complex a language, omission of certain medical data about the patient, giving false hopes, contradictory information, impersonal tone adopted to deliver the news.

For the abovementioned reasons, ever since 2002 the American Academy of Paediatrics and the American College of Physicians drafted the following recommendations for Emergency Departments [18]:

1. Doctors should grant psychological and emotional support to families while respecting their social, cultural or religious diversity.
2. When a child dies doctors should use a support team and a family centre (support group).
3. It is necessary to introduce training programmes so that the staff have a coordinated answer when the death of a child occurs.

Good Practice Guidelines may prove to be a useful, easily accessible tool for the MD. The Guidelines

comprise recommendations, not strict rules, structured in three main chapters [19,20,21,22]:

1. How to approach the parents of a dying child?

- Call the child by his/her name.
- Do not give false hopes to parents and tell them the whole truth.
- Prepare parents for what they are about to see before taking them to the child's room.
- Ensure parents that everything humanly possible is done in order to save their child.
- To the extent possible, allow parents to take part in the process of taking care of the child.
- Give answers in a plain language. Be prepared to answer questions such as: "Is my child in pain?"
- Give the family the possibility to opt for organ donation ensuring them that the patient shall be treated with maximum attention and dignity (subsequently most parents appreciate this proposal even if they do not consent to organ donation).
- Leave parents with their child in the moment of death, if they want to (only applicable in those cases where the department policy allows for parents to assist to resuscitation manoeuvres).

2. How to announce the family about the death of the child?

- Do not delay the moment of communication! You must deliver the tragic piece of news to the parents as soon as possible.
- Reassure the family that everything possible has been done to save the life of the child.
- When referring to the child, use his/her first name.
- Tell parents everything you know about the medical condition of the child and the events having led to his/her death. Give a minimum of medical data on the cause of death.
- Understand that in the first place parents will not accept the news easily. Due to the emotional stress, they can hardly grasp something from the initial explanations: be tolerant and repeat the information.
- Be aware of the fact that some parents cannot accept the tragic news initially and they go on denying reality; when the family is ready, this mechanism of emotional protection fades away.
- Expect a wide range of potential reactions from the part of the family: from an apparent detachment to violent reactions (sometimes against the medical staff). Do not fight back.
- Allow parents to cry.
- Express your frustration and sadness related to the death of their child. Do not try to suppress these moods: they will charge you in a negative way and the empathy between you and the family runs the risk of turning into a conflict situation.
- Do not avoid the physical contact that can offer

comfort and consolation. It is not wrong if you feel the need to hold the parents' hands or to embrace them for a short moment.

- To the extent possible do not leave as soon as you finish delivering the news; take some time to answer potential questions and to give emotional support.
- Do not recommend sedatives to alleviate the pain (most of the parents who sought this remedy regretted it afterward).
- Ensure privacy for the parents and the possibility to stay with the dead child if they want this. In this case, take the necessary measures to prepare the body so that it no longer bears the traces of medical manoeuvres (catheters, electrodes, bandages, intubation probes etc.).
- Encourage parents to address the child and talk about the child.
- Accept cultural and religious differences which are part of the family tradition.
- Inform the parents on the legal or medical procedures (e.g. autopsy). Provide assistance and support for these procedures. Give parents the possibility to hold the child in their arms before and after necropsy.
- Inform parents on the possibility to benefit from psychological counselling.

3. DON'Ts:

- Do not say: "I understand what you feel" or "I know what you are going through" even though you may have gone through similar personal experiences. The grief of a parent cannot be compared to that of another parent, as it is a singular experience.
- Do not say: "you'll get through this". In a moment like that, this statement is equal to asking parents to bury all memory of that child together with his/her coffin.
- Do not offer consolations such as "you're young, you can still have babies". Each child is unique for his/her parents.
- Do not ask parents to say more than they are willing to. It is not good to force them; wait until they are willing to or until they are ready for it.
- Do not avoid grieving parents.
- Do not wait for the parents to seek for your support. They may not be able to ask for your help or tell you what it is they need.

Professional Training and Psychological Support for the Medical Staff

For the medical staff who take part in the death of a child the experience is traumatizing and many MDs or nurses are left with the doubt that they did not do everything in order to save the patient. Paradoxically, the number of training programmes in this respect is very small, and the lack of specific training suddenly positions medical staff in a difficult situation. Thus, in front of the family the MD appears unprepared, hesitating, anxious and lacking self trust. The mechanisms to adapt oneself to these confron-

tational experiences translate into instinctive defence reactions against psychological traumas: the tendency to take a step back from the patient's suffering and family grievance, cognitive strategies or involuntary behaviour with the aim of mitigating the MD's psychological trauma. Surpassing protection mechanisms as a consequence of repetitive exposure to stress factors and emotional distress leads to the occurrence of the phenomenon of burn-out [23,24]. Expressions of the burn-out phenomenon are: depression (sometimes suicidal tendencies), irritability or even anger, sleep disorders, diet problems, headache, apathy, chronic fatigue, emotional distress, sharp defensive mode and tenseness, addiction to substances, conflicting relationships with peers or family, negative self-assessment, sometimes the decision to quit one's workplace (seen as the only possible way of solving the conflict state). Solutions for containing the phenomenon of burn-out entail a wide range of measures, beginning with a review of the selection process for staff employed in the risk sectors (Anaesthesia and Intensive Care Unit, Emergency Department, oncology etc.), ongoing peer support, staff training for the management of difficult psychological situations, prophylactic and curative psychological counselling. The coordinator of the medical team, much like the conductor of an orchestra, bears the fundamental role of signalling tensions at the level of the team or at the individual level and appease such tensions. Therefore, during the process of activity analysis, he/she must ensure the staff reporting to him/her that the medical activity was done in compliance with the set procedures even in those cases where the patient died, but – at the same time – he/she must find a way to improve staff performance without deepening the feeling of guilt signalled at an individual or collective level.

Given the importance of aspects stated, the authors of this article initiated a pilot project in Romania with the main objective to improve communication with the family of the dead child. The number of participants in the course reached 50 medical staff (MDs, medical assistants, psychologists, social workers) from the departments of Emergency, Anaesthesia and Intensive Care and Pediatric Oncology. During the course all theoretical aspects summarized in this article were tackled, alongside with practical aspects, and the trainees were familiarized with real-case medical scenarios through role-play exercises. Results were very positive in that all participants highlighted in the final questionnaire the usefulness of such training programmes for the medical staff. The participants agreed that the Romanian College of Physicians in collaboration with the Administrative Boards of the Faculties of Medicine should analyze the possibility to introduce these courses at the post-graduate level but also for students in cycle II of undergraduate medical studies. Results shall reflect an increased level of patient satisfaction as well as less psychological pressure upon the medical personnel exposed to extreme stress generated by such events.

In conclusion, acquiring communication skills for extreme medical situations represents a stringent necessity acknowledged by both the medical staff and the patients or their families. In an era where "healing has been replaced by treating and the art of listening by technological procedures" [25] it is the time to approach the patient in a manner in which he/she can feel that he/she is being treated as a human being and not as a medical problem.

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