



Unmasked end-of-life care

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ABSTRACT

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INTRODUCTION

Unmasked face of dying or rather the real face of dying, death, end-of-life care (EOLC), mean many different things considering somatic, psychological, social, and spiritual dimensions of the whole person; total pain or suffering and attitudes or feelings of the dying person and those persons involved with the dying, their beloved, the caring team, and the strangers - observers) (1,2). Probably all of us wish to die a "good death" free of needless suffering (pain, dyspnea, or other distressing symptoms) and be supported by our beloved (3). But nobody knows what we might do face to face with death and its darkness. "I know only three alternatives: distraction, despair, and hope" (4). Facing inevitable death of the patient, the relatives asked us to do everything to make sure that the suffering of the dying person was well alleviated. They also wanted to receive last, very important message from their beloved ones. That is often difficult to obtain. As palliative care providers we also think about scenarios of our family members dying. We would like to ensure that it is peaceful for our relatives as well as our patients; thus we should do everything to broaden our knowledge and improve our skills, and to teach other professionals to be well prepared for practicing EOLC.

Suffering of dying patients is probably, in the majority of cases, masked and difficult to discover especially in patients close to the agony. According to observation of Ventafridda, 70% of patients partially or fully lose consciousness in the last 24 hours of life (5). Osler found the signs of pain and distress only in 20% of 500 dying persons (6). Those data that describe the time of agony (about last 24 hours) and completely ignore the suffering of the family cannot calm us. It is obvious that in the last weeks or days of life majority of the dying experience increasing suffering which often remains unrelieved, including somatic complaints (pain, dyspnea, nausea, anxiety) and spiritual and existential suffering. It reminds us that we have to improve our skill in understanding the language and often hidden suffering and needs of the dying and their beloved and to improve our EOLC (2,6).

LEARNING FROM WORK EXPERIENCES

During 45 years of my professional work in different settings and specialties I was usually encountered with three different attitudes of doctors towards dying patient:

1. Avoiding or keeping very short contact with the dying and often excluding communication with the relatives.
2. Medical contact aimed to recognize if the patient is suffering physically (pain, dyspnea, restlessness) and if he/she needs some medication to relieve it. This temporary intervention, called medicalization, deals only with physical symptoms. Medication is seen as a universal approach to relieve all kind of the patient's suffering, including death, anxiety, and spiritual pain.
3. Palliative-hospice care approach is an attempt of holistic care of dying patients and their relatives whenever we get their consent. It encompasses communication and tactful reaction to patients' complains, continuous symptom and distress monitoring, anticipation of family concerns, their reactions and expectations; it also includes pastoral service, prayer, and rituals.

While giving consultations in many hospitals for patients at the end of their lives I am often surprised that the medical professionals themselves are not aware that the patient is dying, although there is a clear diagnosis of dying. Learning from one's workload, caring for the dying together with more experienced caregivers, sharing skill and knowledge gained by palliative-hospice care is an obligatory task in order to improve the EOLC.

Care of dying persons, including communication and symptom control, is in general still unsatisfactory. SUPPORT and other studies (1,7) show dissatisfaction of the bereaved families reporting that their beloved ones died in unrelieved pain, psychosocial and spiritual needs were not met, and measures prolonging the process of dying were continued without patients consent.

Our knowledge of the language of dying is poor. By guessing from non-verbal clues, often

very limited (grimacing, crying, lips, head and hand movement) - we search for answer to our questions: Do you feel pain, dyspnea, discomfort, and numbness? Should we change your position in the bed? But what about sharing the spiritual pain? We have not discovered yet a useful tool for communication with the dying. The use of nonverbal clues (applicable also for evaluating level of consciousness or sedation in old and demential patients), which certainly are not ideal, could be recommended in communication with dying. As a doctor you can be supported by the family members and the nurse who by touching the painful bodies of patients usually understand their messages much better than the doctor who visits the patient less often and for short time. I am of the opinion that the doctors and nurses who take care of the dying often provide the family members with false information that the patient does not suffer (they are not sure whether the patient is complaining) because of the communication problem named above.

Usually, the relatives and primary caregivers, often abandoned by health services, are the genuine witnesses of dying. Advanced, progressive disease has widespread negative impact on family life. Factors contributing to the distress of the family members include the following: suffering emphatically with the distress of the patient and his/her physical illness (symptoms, disability, and therapy), family dynamics (family stability, conflicts in the family, inability to work cohesively), impending loss and bereavement (finding a way of living together in anticipation of death of beloved), role changes; burden of care: separation, hopelessness, sense of futility, meaningless, concerns about death, religious concerns (illness as a punishment) (1,2).

Palliative care training program implemented to the curricula of Poznan Medical University students started 14 years ago (8). It is focused on raising the student's awareness on the multidimensional nature of suffering in dying patients; distress of their families; factors increasing suffering associated with inappropriate attitude; lack of skills in palliative care among medical professionals; communication and empathy; importance of discovering one's own emotions and limits and own resources and abilities to alleviate suffering. Practical training in hospice and home care setting, supplemented by case discussion and debate about difficult ethical questions, allows students to face the unmasked EOLC and possibility to alter the course of dying by alleviation of suffering and giving support to the family. Osler (6) indicated many years ago that learning from experiences is an important part of retaining skill, and should be implemented to the curricula of undergraduate and postgraduate training, not only for those who are obliged but also to those who will have the privilege to be chosen to provide care for the dying.

CONCLUSION

From the perspective of my long 17-year experience in palliative care I would like to propose some conclusions:

1. Dying and death as well as end-of-life care have various unmasked and more or less masked faces, every time associated with suffering.
2. To support the dying and their relatives, especially those who suffer existential pain, is very difficult task for doctors and other members of interdisciplinary palliative care team, including the chaplain. Spiritual pain often unexpectedly increases at the end of life, and can even be potentiated when physical symptoms are well controlled.
3. Reflective thinking using the work experiences is of great value in holistic care.
4. Communication skills are very important especially emphatic listening to understand the story of suffering both from dying patients and from their relatives.
5. In the contact with the patients and their families, especially if it is the first one, it is very important to create your own picture of the situation: What do I see? What do I feel?; What would I like to do to relieve suffering of the patient and relatives?; Do I need any support

from our colleagues?; Am I exactly the right person who can help; Who is accepted by them?

6. It is important to be aware about the prognosis, how close is the death (diagnosis of imminent death) to be able to prepare the patient for dying and the family to bereavement. Anticipation of dying scenarios will be helpful in immediate relief of very distressing symptoms (suffocation, catastrophic bleeding, delirium, terminal anguish).

7. EOLC should be accessible for 24 hours and seven days a week. Every decision about the place of care, dying and management should be discussed and accepted by the patient and their families.

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