

APPLICATION OF AUDIOVISUALS IN THE COURSE "MANAGEMENT AND ETHICS OF HOSPICE CARE"

Aleksandrova S.¹, K. Statev²

¹*Department "Social and Preventive Medicine, Pedagogy and Psychology",*

²*Department "Healthcare management, Medical Ethics and Information technologies",
Faculty of Public Health, Medical University - Pleven, Pleven, Bulgaria*

Reviewed by: Assoc. Prof. S. Popova, MD, PhD

ABSTRACT

In Bulgaria, The Healthcare Establishments Act has officially introduced the concept of hospice care in 1999. Since then many hospices have been established and the interest in them increased. The course "Management and ethics of hospice care" was introduced into the master programme of specialty "Health care" in Medical University - Pleven 2002/2003 academic year and 2003/2004 academic year into the bachelor programme. 83 master degree and 107 bachelor degree students have passed the course. The aim of this paper is to present the application of audiovisuals in the course "Management and ethics of hospice care". Planed as interactive course, in parallel with the traditional approaches, three Hollywood movies have found their place in the programme: "Sweet November", "Autumn in New York" and "My life". All of them represent stories of terminally ill young patients but with different focus on the issues related with palliative care. Bearing in mind the delicacy of the discipline and the impossibility of contacts of students with terminally ill patients, the application of audiovisuals in the course "Management and ethics of hospice care" contributes to understanding the gist and philosophy of hospice care. The aim of the course is to prepare professionals who have "ear" to hear even what has not been expressed, have "mind" to understand what has been said and have "heart" to respond to what has been understood.

Keywords: audiovisuals, management and ethics of hospice care.

INTRODUCTION

The progress of medicine turned death into treatment failure so that it is not seen as natural part of life any more. We converted death into our responsibility and mistake. But it turned out that death is not conquered! What can we propose to the patient when cure is not available and death is inevitable? Palliative care is the option to be proposed in such situations.

According to the definition of WHO from 1990, palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual symptoms is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. It offers a support system to help the family cope during the patient's illness and in their own bereavement (10).

In Bulgaria, The Healthcare Establishments Act has officially introduced the concept of hospice care in 1999. Since then many hospices have been established and the interest in them increased. Consequently, a need for more knowledge in the field appeared. The course "Management and ethics of hospice care" was introduced into the master programme of specialty "Health care" in Medical University - Pleven 2002/2003 academic year and 2003/2004 academic year into the bachelor programme. 83 master degree and 107 bachelor degree students have passed the course.

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AIM

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The movies

Planed as interactive course, in parallel with the traditional approaches, three Hollywood movies have found their place in the programme: "Sweet November", "Autumn in New York" and "My life". All of them represent stories of terminally ill young patients but with different focus on the issues related with palliative care.

In "Sweet November" Sara, who is suffering from leukemia, dedicates herself to the mission to help people realize what is worth in life. This is a film about the philosophy of life, about the real things in life. Although the film doesn't emphasize concrete dimensions of palliative care, it contributes to the understanding of hospice care philosophy. The film also illustrates one of the ideas of "good death", the so called positive effect on one's family.

"Autumn in New York" illustrates the desire for life. In contrast to Sara, who refuses active treatment and tries to squeeze what is left from her life, Charlotte decides to fight till the end and signs "living will". She agrees to "heroic operation" even with the slight chance of success. The contrast between the two stories is looked for in the teaching process. A strong moment in "Autumn in New York" is the illustration of medicine's helplessness. These two movies are shown to the students in the first half of the course. The film "My life" is the end of the course "Management and ethics of hospice care". It encompasses all dimensions of palliative care intertwined in a real life story.

Palliative care elements illustrated in the movies

There are many elements of palliative care shown in the three movies. I will consider briefly several of them: truth telling, phases of psychological reaction of the patient after communicating the terminal diagnosis, the living will, the role of alternative medicine, the relatives, and concept of "good death".

Truth telling

Ethical communication of information has several components:

- Appropriate words (understandable to the patient and the family).
- Appropriate manner (gentle, respectful and compassionate).
- Appropriate place (predisposing to privacy without undesired interruptions).
- In the presence of beloved ones
- Appropriate moment (2).

In relation with the last point is the work of the American psychologist Elizabeth Kubler-Ross, who distinguished 5 stages of psychological reaction of the patient after communicating the diagnosis of terminal disease.

Phases of psychological reaction

1. Denial. It is a defending psychological mechanism that plays the role of buffer after the unexpected shock and allows patients to recover and mobilize their internal resources.
2. Anger: "Who you think you are? Do you think you can take away my hope like that? Let me tell you something. That's all I have. You got it? That's all I have." (11)
3. Bargaining. In this stage patients try to gain more time, to do things that were postponed all the time, to reestablish broken relations. Bob Jones finally tries the train of death in the fun-fair. He goes home after 20 years of separation to straighten out the relationships with his parents (11).
4. Depression - this is moment is considered when we say "appropriate moment for truth telling". In the depression phase the patient is prone to suicide. Here is the role of health professionals to support the patient. So communication of diagnosis should be done early enough to have time for creating atmosphere of trust and help the patient to pass through the phases.

5. Acceptance of the inevitable. Stage at which the patient manages to be at peace with him/herself. (1)

Living will

The living will is an expression of the expansion of the autonomy of the patient in situations when he/she won't be able to express his/her views and wishes in regard to treatment alternatives. It is widely discussed issue (3, 6, 7). Both advantages and disadvantages of the living will are pointed out. In "Autumn in New York" Charlotte initially had signed a directive forbidding any form of "heroic intervention" to save her life. She didn't "want to give hope when there isn't any" (9). In the light of new circumstances though (meeting and falling in love with Will) she changes her decision: "I'll do whatever I have to do. I'll tear up the papers. I'll tell the doctors. Whatever you want because I really want. . . I don't want to leave you" (9). On the one side, we can see in this example the relativity of the living will. It is prepared for a hypothetical future moment and till then it can change under the circumstances. On the other side, living will can facilitate decision making when the patient is not competent any more.

The role of alternative medicine

Multidisciplinary and holistic approach of palliative care gives place to alternative methods of treatment as well. Their role is not to cure the incurable but to relieve psychological suffering and to help the patient to find peace with him/herself. "Do you want to carry so much pain in your next life? - the Chinese healer asked Bob Jones. The last second of your life is the most important moment of all. It is everything you are - ever said, ever thought - enrolled into one. There is the seed of the next life. Until that last moment you still have time. You can change everything. You can get out of what you feel. You can get out of anger" (11)

The relatives

The relatives are always there around the dying person but sometimes their worries are not properly addressed. They could have different worries and many questions:

- What is going on with the patient?
- Why the patient receives particular treatment?
- Is the disease catching?
- Would they be able to provide proper care to the patient?
- How long they can take care of the patient at home?
- How to talk with the patient about death and dying?
- Would they manage with emergency situation if such happens?
- How and if at all to talk about the disease with the children and family friends?
- How to cope with intense family moments?
- Bothering unresolved personal conflicts from the past etc. (5)

The relatives could have worries about their own health status but feel uncomfortable to share them because the patient is worse and dying.

This is a stressful situation for the relatives as well as for the patient him/herself. They don't know what to do, how to approach the patient, how to put in order their own minds and feelings. "I am here for you any time. Your silence isn't protecting me, Bob. I feel like I've lost you. Like we've lost each other. I need you. I can't do this alone. I need you to be there. - How can I be there? - Bob asked. - Let me inside. Share what you are feeling. That's all I need. - his wife answered" (11).

The concept of "good death"

We may all have some idea about the best way to finish our life. The idea about what might be called characteristics of a good death may be very different from person to person. Here I will point out: peaceful death, in-time death, death in our control, dying in one's sleep, dying at home, dying in the neighborhood of significant others, and positive affect on one's family.

Peaceful death: death free from physical pain and other unpleasant symptoms, death in peace with God and one's neighbor.

In-time death: related with the idea of "full biography"; death that occurs in a moment when the person has fulfilled his tasks, solved interpersonal conflicts and satisfied personal wishes.

"Death in our control": the good death is the one in which the patient makes his/her own choices about his/her last days.

Dying in one's sleep: death takes place in a moment when the person has a lower degree of consciousness; there will be no psychological distress or fear as it might be in the conscious waiting for death (4).

Positive effect on one's family is a philosophical concept including acceptance of death by the whole family; reminding good moments together; farewell with the conviction that the beloved ones will manage to continue further. A remarkable illustration of this concept is the last scene from the movie "Sweet November" in which Sara wants Nelson to leave her in a moment when she is still feeling relatively well.

"- Sara! Sara, stop running! Sara! Sara, please. I'm not leaving you. I know you love me.

- I do. I've never felt anything like this. I've never thought I'd have the chance and you gave that to me, Nelson.
- Than why you are doing this?
- Because it's starting to happen.
- I don't care.
- Nelson, if you leave me now, everything we had will be perfect forever.
- Sara, life is imperfect.
- All we have is how you remember me. And I need that memory to be strong and beautiful. Don't you see? If I know that I am remembered that way, than I can face anything. Anything. Nelson, you are my immortality.
- I want to take care of you, Sara.
- I'm going to be all right. I'm going home. They know I am coming. I need to do this.
- This just doesn't seem...
- Just like I need to know that you go on and have a beautiful life. The one you deserve.

- I only want you.
- You have me... forever. Now let me go.
- All right, Sara. All right.
- Close your eyes
- I love you, Nelson Moss.
- I love you, Sara Devar.
- Remember me!" (8)

CONCLUSIONS

Bearing in mind the delicacy of the discipline and the impossibility of contacts of students with terminally ill patients, the application of audiovisuals in the course "Management and ethics of hospice care" contributes to understanding the gist and philosophy of hospice care. This also increases the sensitivity of the students to issues of death and dying. The aim of the course is to prepare professionals who have "ear" to hear even what has not been expressed, have "mind" to understand what has been said and have "heart" to respond to what has been understood.

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