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Perception and attitude toward end of life in Albania

Abstract

Background. The main aim of the study is to explore the perceptions and attitudes of health professionals, patients' relatives and general public regarding end of life issues.

Materials and methods. The authors have used the qualitative method as suitable approach to reach the goal of the study. The sample is 140 participants respectively; 56 health professionals, 60 patient relatives and 44 people from wide public. There were developed 15 focus groups discussions in 7 main cities of the country; 4 with health professionals, 5 with relatives' of cancer patients and 4 with general public.

Results. Most of the patients relatives, general public and health professionals defined easy end of life as: to be treated with dignity and respect; being auto-sufficient; living in a family environment; being close with friends and family members; living without pain and suffering. Most of physician don't tell the truth to the cancer patients asserting that: familiars don't allow them; the low health culture among population affects their perception and attitude on this topic; communication issue have not been part of curricula; and most of them are not trained on how to tell the truth.

Conclusions. Main findings of the study are: Albanian Society is not prepared for a real assessment and proper solution to the end of life issue. The fact that there is nothing beyond death is the main reason for fear. Albanian health professionals are not prepared to communicate the terminal diagnosis to cancer patients.

Key words: end of life, death, health professional, relatives, tell the truth

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Introduction

End of life care is an important part of palliative care (PC), and usually refers to the care for a person during the last part of their life, from the point where it has become clear that the person is in a progressive state of decline [1].

In Albania PC is a new and limited service, available only for terminal cancer patients. Recently the incidence of cancer is increased significantly, in 2010 there were 5000 new cases with cancer and approximately 70% of them became part of PC treatment [2]. In 2009 the need for palliative

care increased with 57% in comparison with the year 1994 [3, 4]. PC is facing several challenges in Albania as: being an integral part of health care system; approaches on how the patients and their relatives are experiencing end of life; patients and relatives avoid discussing about death and dying, diagnosing disclosure and information.

Death still remains a taboo topic of discussion in Albania culture. Death and dying have, in general, become a more private and detached affair, with the level of fear and anxiety attached to it greater than in previous times [5]. Although culture is an important factor in attitudes towards death and dying, one

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must be careful not to overstate its importance. At the micro level this could lead to stereotyping when trying to predict individual behavior, which would be unhelpful and inhibiting [6]. It may be important to consider these cultural issues when thinking how to approach discussion of end-of-life care, the expression of pain and the role of the family, as well as accounting for individual issues.

In PC service, the role of family is very important. Albania society is a family centered model compare with western model which is one of individual autonomy. Western societies tend to favor a model of autonomy and openness, which encourages honesty and opens the way for communication [7]. The preference for this model seems to reflect general cultural attitudes of individualism and a belief in an internal locus of control (that we are in control of life events and circumstances) [8]. Encouraging openness in societies where this is not the case may be much more difficult, though not impossible if education and communication skills become more widespread [9].

High percentage of cancer patients are not informed on diagnose and prognosis and part of this is related with the past health model. During the communist regimen the physician was not allowed to tell the truth to the patients. Even in some countries of Eastern Europe, there are problems with truth telling in relation to diagnosis of life-threatening illness. From study of hospices and related developments in Eastern Europe and Central Asia and noted that "Soviet medicine" discouraged a holistic view of healthcare delivery. This still pervades today, as well as negative stereotyping of cancer and the care of the dying [10]. However, a national study in Korea found, 'a strong wish for disclosure among the patients themselves, and significant differences in attitude between patients and family members therefore, caution should be applied in holding to the family-centered model rather than exploring the patient's wishes' [11].

The aim of study is to explore perceptions and attitudes of health professionals, relatives of cancer patients and general public regarding end of life.

Material and methods

To reach the aim of the study was undertaken a qualitative research method. The sample used in the study is 140 participants of age group from 45–60 years old. There were developed in total 15 focus groups in 7 cities in the country, respectively 5 with familiars of the terminal cancer patients,

5 health professionals and 5 general public i.e. individuals who not necessarily were affected by the cancer disease.

Data collection was done during June – December 2009, transcribed and treated carefully in order to guarantee the anonymity of the individuals involved in the study. Group discussions lasted one and a half hour with 8 to 10 participants. 20 deep interviews were developed with members selected from the focus groups to check interpretations.

Main questions were about their perception and attitude on life and end of life. How they face the death issues, does they discuss on that? If yes, when and with whom? What are the characterizes of their own knowledge and experience for such issues and their perception and attitude about telling the truth?

The findings and recommendations of this report may not represent the opinions of all the people suffering from a terminal disease or providing palliative care. The generalization was not the goal of the study.

Results

Perception and attitudes on life and death

The great majority of participants defined the 'good life' as being healthy, having children, good relationships with familiars, good economical situation, good job and carrier.

Though there is not any formal definition for what an easy end of life is, for the most part of participants it means: to be treated with dignity and respect; to be auto-sufficient; to live in a family environment; to be close to friends and family members; to live without pain and suffering. In general pain free was not the first association the participants made with the "easy" end of life.

It is interesting to observe how close they perceived the end of life, to the others appreciation with expressions such as "have done only good in their life", "are leaving a very good reputation behind them" and "their children are settled". *A relative asserted that "Good end of life? ... When you leave behind a good name. When you have done good things in life. When You have been surrounded by loved ones, when everybody loved you.*

The main concern of most of participants seems "not to be a burden for no one", stressing that caring process in all the dimensions of life is difficult and tiresome for the familiars. They would like: to have somebody close to them in their last moments; wishing to leave the life "at old age" and children should not pass a way before their parents.

Results show that main factors which would make the end of life “not a good one” is: being alone or abandoned; being mutilated; not having enough financial means and suffering from illness. Few participants, who haven't terminal disease experience in family, during group discussions about life perception, were free-and-easy, more relaxed and philosophic compare with those having such experience.

The participants in the study did not feel comfortable to talk on death topic. They would very seldom prefer to think about death, which is accepted as a reality, but it is kept with fear in subconscious. *A familiar quotas “Nobody likes to have death experiences. Loosing somebody close to you is very difficult, this is out of question. It becomes more difficult with our customs and terrible rituals. You can notice that intellectuals take it more easy. The respect for somebody close to you is not expressed through wail with weeping...”*

One of the greatest resources for changing attitudes to death by reducing denial is the hospice movement [12]. Hospices encourage living as full a life as possible with the knowledge of terminal illness, with the goal of a “good death” in mind. A “good death” in this sense is one in which, *‘people are viewed as having spiritual, emotional, intellectual, social, cultural, interpersonal and economic components to their lives* [13].

Regardless the facts that people do not think very often about the end of life, during every day life the people easily use the term “death” in “I love you so much than I can die” “I am ready to die for you” “Let death take me”, but on the other side they are too restrained in using it in serious situation.

Health professionals perceive that the end of life concept has started to change; it is not seen as a terrible thing, now it is seen like something more normal and natural.

Preparation for the end of life

From group discussion was comes out some local habits that in the past the brides used to take the last day clothes within dowry and elderly used to have a suitcase with the dressing for the last day. Preparing the last day dressing early in youth age, may show a silent acceptance of the end of life.

Most of participants' quoted that they avoid talking on death and dying with their friends, colleagues and relatives. Older generations do not speak to younger generations about that, they even do not like to think about it. This is also reflected in daily activity behaviours such as: lack of life insurance,

not making a testament or not saving money for the last day. This kind of facts you may find even among wealthy people. In Albania society, there is a lack of using Advance Care Planning (ACP), which allows patients to confront and accept the prospect of death. It is far more than a tool for dealing with the physical and practical aspects of death, as it is the ability to deal with psychosocial aspects that patients appear to perceive of greatest benefit. ACP allows patients to gain a sense of control over, and find meaning in, their lives, as well as strengthening personal relationships.

Even we are regularly bombard with images of death from media, their presentation takes a detached form which leads one to believe that death only happens to others [14]. Many participants emphasize the role that media must play for providing the people with the right information about this stage of life.

Health professionals point out that there is a low level of health culture among population, which affects their capabilities to better understand and openly accept the end of life.

Fear of death

The interviewers stress that fear of death is usually accompanied with other fears which follow a disease, such as isolation and loneliness. Exploring into more details, were found that fear of pain is bigger than the fear of death itself. Expressions like “within three days in the grave”, “one attack and in the grave”, illustrate very well that people are afraid of pain and they do not want to suffer for a long time in bed, they want to have a painless end as quick as possible. High level of participants stress that: people who have made their dreams and wishes come true are less afraid of death and; people would suffer much more in the end of the life, if their children would not be settled or if they wouldn't have managed to have some of the basic elements in their life such as housing, marriage and children's' marriage.

In a study of ACP it was noted that, ‘fear caused participants to have a greater desire to control their treatment decisions and the dying process. Advance care planning provided a language and framework that helped participants organize their thoughts and articulate preferences, which was a first step in achieving a sense of control’ [15].

Religion and death

It was seen that believers talk easier and more frequently about death; they are prepared better for it. They think that life in this world is temporary

and quietly look forward to the life after death. Non-believers, who make the most part of population, are more hesitant; they avoid or talk less about death. The unknown beyond the death makes them more scared and anxious. A nurse quota *"We were a generation at risk because we grow up our kids out of a religious environment. It was a misfortune when religion was prohibited in our country. Religion represents the hope of God; it strengthens people's hope, character and gives them courage. I was 25 years old when they prohibited the religion; at this age I had already taken in the power of God."*

Dilemmas on breaking bad news

In Albania more than 80% of cancer patients are not informed about diagnosis and prognosis. Those few, who are aware of it, usually are people with higher education, with high level of medical culture and those who are diagnosed outside the country. However, this cultural shift is set against the seemingly contradictory finding that, in developed countries, those with terminal illness would like to receive their diagnoses and be more involved in end-of-life decision making even though this may not always happen [16].

Among medical staff and general public there is not any accordance if the diagnoses would be told to the patients or not. Even health professionals, who support the alternative of telling the truth, would not have enough courage to do it themselves. *A physician quota "It is normal that even the people who psychologically are very strong, are shocked by such news ... it is normal, it is a shock, the life is going to be interrupted. The question is to overcome as soon as possible this situation"*.

Training of healthcare professionals in techniques such as open questioning, active listening, reflection and paraphrasing can open up patient-professional communication and pave the way for truth-telling [17, 18]. One other essential task is to balance the giving of information with the maintenance of hope [19]. Yet one must be mindful of the fact that encouraging autonomy includes autonomy to take the decision to refuse information and direct others to make decisions [20]. According to the doctors, even in cases when the patients are suspicious about death, they still have hope, which is attributed to the power of medicine. Maintaining hope has been a central issue in dealing with death and dying [21].

Most of patients' relatives and general public think there is no reason for the patients to know the diagnosis. They believe that learning the truth

aggravates their emotional state. Some others believe that this may become a reason for patients to decide on committing suicide. Convinced of that fact, relatives don't allow the doctor to tell the truth to patient. *A relative quota: "we both went to see the doctor, he was insisting to tell him the diagnosis and the therapy he should apply.... I urged the doctor not to tell him the truth about the disease"*.

Somehow, this is typical for patriarchal families we still have, where decisions within family are taken by one person or two. Some of the familiars say that in this way they share the pain with their patient stressing that: *"She/he is suffering enough with the physical pain; let us take upon the psychological one"*.

Most of the professional staff points out that the Albanian mentality and circumstances cannot manage it and have insufficient preparation to manage the reaction of the patients.

A physician quota: "You must not tell the patient he has got cancer and he is going to die. This is absolutely a crime taking into regard the living conditions we have in Albania."

According to doctors, in most of the cases their attempts to tell the truth are hindered by relatives. They try to give more hope and courage to patients, even their work becomes more difficult as the patients do not cooperate. In Albania society the family is a focal unit, and therefore it is common for interactions between healthcare professionals and the patient to be channeled through the family.

Discussion

Albanian Society is not prepared for a real perception on end of life. Albanians behaviors attempt to divert the real assessment and conception on death and dying. Neither families nor social institutions inform the people about death during their life. Having an ill person in family and care giving change the way how you perceive life, health and death. It is apparent that changing attitudes to death and dying is never easy, and certainly never swift.

The fact that there is nothing beyond death is the main reason for fear. This fact distinguishes the believers from nonbelievers and atheists. Most part of the population does not believe in God and they fear death as the end of the end. This is certainly a hypothesis to be examined further.

Albanians in general repress the thought of death. Albanians fear not only death, but pain as well. Being a terminal patient, familiar of a terminal cancer patient or a medical staff is a determinant factor for awareness of pain.

In general the terminal diagnosis is not communicated by the doctor believing that the mentality of our society can not manage it. Most of the doctors consider the low level of education, and culture as the determinant factor for communication of the diagnosis.

Albanian doctors are not prepared to communicate the terminal diagnosis. Doctors themselves are part of the mentality they consider "unprepared". Communications issues are not part of the curricula's in the education programs and very few of them are trained on telling the truth. The communication skills required in these settings go beyond basic interviewing taught in medical school [22]. Few rigorously evaluated studies of communication skills training have addressed postgraduate trainees [23, 24].

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