REVIEW

End of life

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Abstract

Dying, but not the death, is an essential problem. The more we believe that death ends everything, the more we fear from death. A human spirit only hardly copes with this fact. All religions want to cut this fear. They highlight that present life continues and human spirit lives further on, in another postmortem dimension.
Authors evaluated death of 142 patients, among which 45 (32 %) died at home, 74 (52 %) in hospital, 34 (24 %) died among family relatives and 56 (39 %) without the presence of relatives.
Most of the dying patients wish to stay with their family or relatives at the end of life (end of life decision). If this wish cannot be fulfilled, then a palliative care seems to be the most suitable alternative for an individual in terminal stage in modern society.
In the Presov region, there is a lack of hospices and palliative care does not cover the needs of terminally ill patients *(Tab. 6, Ref. 41)*. Full Text (Free, PDF) *www.bmj.sk*.
Key words: dying, the site of death, palliative care.

Recent changes of life style and values in Slovakia have revealed old and new phenomenon in the field of dying and death. Their solution requires professionally trained medical and social workers, who will be motivated, beside expert skills, by human principles and effort to teach patient to live usefully and meaningfully till the end. At present, with the technique penetrating all areas of medicine and civil life, humanization of health system should be of high priority.

Media and commercial view of death as a business article has shielded everlasting philosophic and religious problem – the secret of death. The last phase of human dying is characteristic by the fact, that none has its own experience and cannot pass it to others, so both professionals and general population miss the experience (10, 37). Most people fear more from dying than from death itself (3).

Insufficient attention is paid to last moments of human life in our country as well as abroad (4, 28). It is certainly a paradox, that while the medical specialization on coming to life – obstetrics – is regularly developing together with other medical disciplines, medical specialization on leaving the life – tanatology – is covered by individuals and practical knowledge in health care workers is generally insufficient (6, 12).

From the view of psychological care, the term death has its own specifications and is at least equally important as the care of somatic problems. Dignified death means that even in the most difficult hour of the life the dying person should not be alone and without open personal interest (34).

Accompanying to death is the most difficult task for everyone (8). The same is true for the clinical geriatrist. This difficult part of work can be successfully managed only by the one who really and without reservations loves people, who is balanced with own finality and own mortality (5). He also needs to know how to add not only his energy and power but also his love and sensitivity in daily praxis. From the patient's view, kindness and sensitivity in doctor's attitude create the faith and expectation that the result will be the good not bad. Compassion and support to dying subjects takes a lot of energy but add a lot of wisdom and maturity (11, 40).

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Tab. 1. Age range of inhibitants in District Lemesany (data from December 2003).

Number of all inhabitants	2296
Number of inhabitants older then 18 years	1309
Number of inhabitants ≥65 years	301 (13.1 %)
≥80 years	38

At present, no common view exists on the site of the end of life. Subjective wish of each individual should determine the site and could be considered as optimum (end of life decision) (1). But what is optimal if subjective wish cannot be guaranteed?

An important factor, which influences the site of death, is the development of one-generation family. Children are soon independent, economically not related on parents and both old and young family lives separately (13). With time, relationships become trivial or independent. In our country, this process is markedly supported by the small size of flats (25).

At present, the doctor should take care of both psychical and social comfort of the patient, including the choice of help to an old, immobile or dying individual. Patient must be informed about all possibilities. Spontaneous choice of help is sometimes not advantageous for patient. In literature, it is called "new social role of a doctor" (7). It means that the doctor working mostly with geriatric patients should be an author and coordinator of all types of help.

Department of geriatrics has been working in Presov region already 23 years. From July 7,1983 to December 31,2005, 2676 patients have died at this department. The aim of this study was to describe the situation of dying not only in hospitalized patients but also in the field of outpatients. The knowledge of actual situation can create a social pressure for necessary development and reaching the optimum in the site of death and way of life at the end in our region.

Aim of the study

The aim of the study was to evaluate the site of death and accompanying people of the dying patients in our region. The district Lemesany was chosen as a sample, because it is a typical district in Presov region (Slovak Republic). The District Lemesany with a private outpatient's for adults, children and dental clinic is located southeast in the Presov region. The region is mostly agricultural, without a bigger factory or other source of environmental pollution. Inhabitant's age range is described in Table 1. 92 % of habitants older then 18 years are the faithful.

Methods

A 10-year pilot prospective study was conducted in the period from Januara 1,1996 to December 31,2005, during which the death of every district inhabitant aged 65 year or older was evaluated according to criteria set in advance. Following parameters were recorded: age, sex, date and site of death, causes of death, family relationships and a presence of close person at the time of dying. The deaths of individuals, who died at different institutions (hospital, social care institutions, private nursing clinics) were also evaluated.

Two individuals, who died due to severe injury during accident and one individual who committed suicide were also included in the study.

One individual who died abroad while visiting relatives was excluded from the study.

In case of death in the hospital, the attending doctor, attending nurse and eventually pathologist were contacted and "Reports on death" were evaluated simultaneously.

Information on deaths in social care institutions were obtained from the head nurse and relatives or from the head of institution.

Every death was evaluated by the general practitioner within 3 working days and then summarized for the calendar years, so the records may be considered accurate.

Due to transparency, 2-year intervals are given in tables (principal data only).

Results

The principal data outline on dead is shown in Table 2.

Deaths due to cardiovascular disorders dominate. Stroke,

Tab. 2. Principal data outline.

Year	1996–97	1998–99	2000–01	2002–03	2004–05	Outline	
Number of deaths	20	36	28	27	31	142	
Males	12	17	16	17	16	78	(55%)
Females	8	19	12	10	15	64	(45%)
Mean age of dead	78.1	80.0	78.9	77.3	81.8	79.2	
Site of death Home	6	14	7	8	10	45	(32%)
Hospital	10	18	16	14	16	74	(52%)
Social care institute	1	3	2	3	3	12	(8%)
Other	3	1	3	2	2	11	(8%)
Causes of death							
Cardiovascular	10	16	13	12	14	65	(46%)
Malignancy	4	4	6	7	6	27	(19%)
Stroke	3	5	3	2	6	19	(13%)
Other	3	11	6	6	5	31	(22%)

Tab. 3. Family relationship.

Year	1996–97	1998–99	2000–01	2002–03	2004–05	Outline
Living alone	4	10	6	10	6	36 (25%)
With partner	8	8	8	16	10	50 (35%)
With other relatives	4	20	8	12	12	56 (40%)

Note: data reflect the last 3 months of life

Tab. 4. Presence of close person(s) at the time of death.

Year	1996–97	1998–99	2000–01	2002–03	2004–05	Outline
With close relatives	5	8	10	5	6	34 (24%)
Without relatives	11	16	8	14	7	56 (39%)
With distant relatives	4	12	10	14	12	52 (37%)

Note: deaths in hospitals also included

Tab. 5. Outline data on dead (District Lemesany).

Number of dead	142	
Mean age	79.2	y
Death at home	45	(32 %)
In hospital	74	(52 %)
In social care institute	12	(8 %)
Other	11	(8 %)
Death with family relatives	34	(24 %)
Death without relatives	56	(39 %)

which also belongs to the cardiovascular disorders are depicted separately, because these patients died at the departments of neurology.

Mean age of dead is approximately about 3 years lower compared to some developed countries (16, 23). Only 32 % of individuals died at home, but 52 % in hospital. In this age category, the percentage of dying due to malignancy is comparable to other countries (31).

As shown in another table, only 35 % of seniors died while living with a partner. Living together with children and other relatives (40 %) is difficult in current economic situation. Up to 25 % of the group has lived alone (Tab. 3).

Despite many difficulties the authors managed to find the presence or absence of relatives or close friend at the time of death. Fifty six patients (39 %) died without the presence of relatives, among them forty one (29 %) in hospital at different departments (Tab. 4).

Outline data on dead are shown in Table 5.

Discussion

For many people, end of life is accompanied by an unnecessary distress, loneliness and loss of dignity (17, 32).

The terminal phase of life may be cultivated only by knowing tanato-psychological and existential base of dying and death (26).

A human in his terminal phase of life has to cope with the fact that he will soon die as well as to manage a brand new, unknown life situation. Dying subject knows that "outside" the life goes on and he belongs to it less and less. His life space is narrowed and contact with friends and relatives decreases. This phase of life is commonly marked with psychical and mental distress worsened by financial, health and life problems, burden from unsolved personal relationship as well as by conflicts and sour towards many people (21).

Face to face this reality, experience and behaviour of the patient are individually different and complex. It is obvious, that the terminal phase of life will be shaped by characteristic personal features acquired during life. In this phase, probably strong and inherited core features will dominate, as self control may be weakened by fatigue, pain or due to disappointment from own infirmity. Two personal features should be highlighted for general personal characteristics and management of dying:

– lability and anxiety as an opposite of stability,
– extroversion as an opposite of introversion.

Using these two personal features, depressive, negativistic and also very sober and active personal types can be described. Emotional lability in stress situation can be found together with negative affects, subjective satisfaction and successful adaptation. This confirms that quality of life and behaviour in dying phase are markedly related to personality (41).

Independently from these empirically determined personalities, doctors and nurses meet patients who behave painfully, intentionally without discipline or humbly, desiring safety. As these attributes together determine an individual, it is important for the accompanying person to consider the variety of personalities and reactions (2).

In accordance with psychology, main human needs are the motor, e.g. the source of energy, psychosocial life and development. Therefore any limitation to these needs should be prevented or balanced. Following are main human needs: need for realiza-

tion, need for award, social need for love and solidarity, need for certainty, safety and bodily physiological needs (14). These needs are hierarchical, from up down. Only after fulfilling bodily needs, the closest need is highlighted and deficiency corrected. Therefore it is necessary to fulfill main life needs first (18).

The main psychological principles appearing at the end of life are following: separating, fear and ability to accept death and dying (26).

1) Professionally trained must gone through separating by a meaningful perspective.
2) Following facts were found in managing fear:
   – fear from death and dying is smaller in old age compared to middle age, in women it is bigger then in men,
   – education, occupation, income, place of living etc. are nearly unimportant regarding fear from death and dying,
   – "emotional lability" positively correlates with fear from death and dying,
   – different relations exist between religious and fear from death and dying.

Using the complex studies on relations between religious and fear from dying and death empirically can be found following:
– fear negatively correlates with faith in God,
– fear negatively correlates with church communication,
– fear negatively correlates with public religious service (worship, confession etc.)

Everything is with 5 % significance. That means that fear from death and dying is smaller in deep faith. Empiric findings show that even people without faith have small fear from death and dying. Individuals with medium faith suffer from fear most (26).

From the view of Christian religious, actual image of God and Christ in dying person should influence managing of fear from death and dying. Regarding fear from dying it is not negligible, whether it is believed in God as a father or as a ruler "Rex tremendus" or whether the image is formed as "Christus medicus" or "Christus iudex". The Christian denomination will have consequences according to the fact whether it is the choice of Calvinistic mentality or credit or catholic sacramental praxis of forgiving or protestant mercy. Trace can be found in life mentality, less in mind. Images and ideas on transcendence and God determine the concept of life as a life plan and therefore managing of the last phase of life (3, 26).

Old Testament assigns death a peripheral sense. God alone is life and source of life. Life is considered as successful relations between man and God and people. By gois rules, the life is reached in its fullness. Problem is an untimely death not the death after a full life. Not a biological death, but current, intravital death is a hostile death power from the view of suffering, pain and misery. Distance from God and life without relationships are parameters of mortal life. When man dies, he goes to Šeol, underground kingdom of death, where he spends unhappy, meaningless existence. Crucial is not the individual existence but the existence of Israeli nation. An individual believes that he exists in his descendants.

There is and idea that bad acts result in mortal experience while good behaviour induce good destiny. However it is important not to understand destiny as monocausal but in the view that man will create a sphere by his behaviour which will bring him fortune or misfortune forever. This sphere is related to individual as well as to whole nation. The act of an individual has consequences for the nation.

This understanding of life with Jahve necessary leads to new reconciliation with death. From the faith in present gift of community with God an idea of an individual antiquation of Death was created. In the view of relation to destiny, those who profane finally perish even when living a happy life. Pious finally finds the fullness of his life in community with God and death cannot change it. At the end of history a final court is expected, by which kingdom of God begins. Not only a pious individual, but the whole God nation will arise to new life at the end of world.

3) Regarding acceptance of dying and death, life experience plays a crucial role together with basic personal attributes. An individual can accept death and dying process as a transport to other life or as an outcome of existence or just as a simple fact.

The question of truth is very important. Various interpretation and rationalization of dilemma: tell or not the truth to a dying person? If yes when and how? There exists a human right to be informed about own life status. Given information is important, but must be individual and delicate. The truth cannot be withhold but also cannot be told as bare and cruel reality. The right moment for the understanding and acceptance of truth is not related to doctor but only to patient. Truth must always be associated with hope. Truth associated with hopelessness kills. Love, empathy and concern are appropriate in this discussion (20). The right balance, that means telling the truth with love, is needed. Faith and hope are important, but most important is love.

One of the first exactly working with accompanying of dying was a Swiss doctor Kubler-Ross. She has described four phases of dying and has been dealing with concomitant experience of those being close to death (20). Accompanying of dying subjects belongs to true life experience, belong to the culture of dignified dying (19, 39).

However even the best life philosophy, the best life plan or optimal cultivated life art in the presence of the most loving approach cannot take the terminal phase of life to acceptable end if the social and medical conditions are not formed (30). We see with fright that during dying process number of social contacts continuously decrease, number of visits decreases, nurses are avoiding rooms with dying patients and are happy when they are asleep. From our own experience it can be stated that agreement with life and following will and desire to life are related to social contacts. The desire to shorten the life and convince about uselessness of terminal phase of life nearly always means calling for inclination.

If it is managed to show inclination and suppress the pain to severely ill patient in terminal phase, then usually his wish to accelerate the process of dying will vanish. Human dignity and meaningful dying depends also on the fact that besides qualified

Tab. 6. Palliative care centers in some EU states.

State	B	D	I	NL	SP	S	GB	PL	CZ
Number of palliative beds	358	989	30	119	812	298	3196	758	170
Home Palliative care	582	88	286	75	67	355	149	–	–
Day care centers	2	9	–	–	–	–	248	8	–

Study Palium–Clark 2000 Abbreviations according to international states codes

accompanying, ill and dying patients remain included into functional human net forever (33).

Most of old, chronically ill people wish to die in home, instead actually die at hospital. Only in some countries is this proportion inverse, e.g. in Great Britain where most ill people not only wish but also die at home or in state Oregon (USA), where only 31 % of dying persons die at hospital (4, 9).

An American analysis on long term ill patients shows the site of death as hospital in 49 %, home or long term care facility where patient feels like "home" in 21 % and hospice in 20 % (28).

The main difference in care at home and in hospital is an overall approach. Hospital care is intended to save the life therefore the patient undergoes various examinations until last moment. For the dying, the laboratory parameters are not substantial, substantial is only the fact how he feels, whether main symptoms: pain, dyspnoe and anxiety are managed. At home, although without laboratory and various catheters, patient is less isolated, has more privacy and his actual problems are solved more quickly (19, 22).

In several publications it is stated that for seniors above 65 years (without cognitive impairment), some situations like life depended on devices, loss of mental abilities, loss of self-sufficiency, permanent pain are worse that death (15, 24).

How to overcome this discrepancy between the desire of patient to die at home, within relatives, and present reality, where this desire is unreal?

A new, humanly highly qualified and differentially developed service is represented by so called hospice and palliative care. Its aim is not to lengthen the life in quantity but to give a qualitatively complex possibility to live even in the terminal phase (34). It is a modern, worldwide quickly developing type of care offering to dying and their family relatives a help when common treatment approaches and also the power and abilities of surroundings often fails (6, 23).

World health organization defines the palliative care as a complex care of patients where the "disease does not respond to the curative treatment". Typical institute for this kind of palliative care is hospice as bed institution or program of complex care provided at home or alternative social environment (27, 29). World health organization declares the palliative care as one of the prior fields of healthcare and social care development (6). Palliative care is also an ethic aspect to counterweight various motions and views to euthanasia (7).

In last years there is an increasing attention attributed to patients not suffering by oncologic but also other chronic and potentially lethal diseases. Approached and experience gained in hospice palliative care in oncologic patients seem to be effective also in other groups of patients. Therefore the concept of palliative care is widening towards new spectrum of diagnoses (e.g. dementia) and broader time period in the course of disease (38). New definition of palliative care (WHO, 2002) is not based on the definition of terminal disease but on the concept of disease which threaten the mind. It is considering the progression of serious chronic illness which is lethal by its final prognosis (29).

Of note, there are also possible difficulties in hospices. Hospices could unintentionally support the tendency of our society to push the problem of death and dying away from life or to expel them and to approve the worrying buck-passing. It may happen that family relatives, neighbours and friends leave the responsibility and care of dying relatives to hospice workers. Therefore hospice should never eliminate relatives and friend from the accompanying of dying but must include them and support this process. Otherwise hospice could miss its own aim and mean (35).

In the USA, home hospice care is considered to be the main form of palliative care, in Western Europe it is the combination of home palliative care and bed institutes of hospice character (9, 23).

Table 6 shows status of palliative care in some European states.

In Presov region, there is one hospice with 24 beds (Bardejovská Nová Ves), home hospice care is merely seldom service provided insufficiently and unsatisfactory by home nursing care agencies (36). Modern trend of complex care of dying person in the setting of specialized nursing institute hospice type with developed palliative care only hardly finds its place in the net of health or social care institutions in Slovakia.

In the Czech Republic during years 2003–2004, a large study was performed on the care of incurable ill and dying subjects, realized by civil society "Cesta domu". The study has confirmed an urgent need to improve the quality of care of dying, radically increase the availability of modern palliative care, develop home palliative care and improve the care of dying in health or social care institutions (16). These aims in terminal care should be the same also in the Slovak Republic. Although traditions and way of life in the Slovak republic are slightly different compared to

Czech Republic, social relationships undergo similar development in both countries during recent years, reflecting character of time. Impaired generation relations and changes of stereotypes bring an ethical problem of care of terminally ill patients at home (17).

Experience based on long term work at the department of geriatrics and situation in present status of health and social care of senior population in Presov region brings the need to realize several changes in present system.

1) At first, it is necessary to deepen and intensify the contact between the general practitioner and geriatric patient. The doctor has to map health status and social conditions of these patients. In case of unsuitable social and interpersonal conditions, this patient must be marked as a risk one.

2) To widen the service of existing home nursing care agencies (ADOS) and centers of home nursing care (DOS) by home palliative care including consulting. To train employees of these agencies in the field of tanatology.

3) Not to limit visits in hospitalized geriatric patients.

4) To include active retiree volunteers to the process of creating a social net for severely ill elderly patients within the activity "ourselves us" according to template from other states.

5) By decreasing the number of acute beds in present system of health care institutes to find a space for hospices with the possibility of complex care of chronically and terminally patients within the hospital.

Conclusion

The way and site of dying in geriatric patients in Presov region are determined by present possibilities and life style. At home dies nearly one third of seniors (32 %), the rest in institutes. Only one fourth of them (24 %) die among family relatives. Among more distant relatives die 37 % of them. Living together with relatives is in present economic situation very difficult, uncertain for the dying person. Without family or other relatives die 39 % of seniors in the region. The mean age of dying is approximately about 3 years lower then in developed countries. Dying in hospices is rare so far. Religious in our region helps dying subjects but less affects those accompanying. New social role of doctors, mainly those working with seniors, is not much realized.

In future, palliative health care should be included into present system of health and social care services mainly in Eastern Slovakia, including bed hospices, and hospices must be supported and its philosophy should be used in daily praxis where the process of dying and death occurs.

Economical problems in building hospices might be overcome by creating a home hospice service, which could provide besides visits consulting, be available on telephone 24 hours a day and be able to locate the patient in an adequate institution. The role of religious institutions cannot be replaced regarding the need for team complex care of dying.

Family member who decide to take care of their terminally ill relatives till the end should be supported, granted from social sources and provided help and adequate education.

It is needed to include tanatology as a part of ethical education into the education at the schools of medicine and nursing.

As in developed countries it is necessary to create a positive social atmosphere for solving problems of dying in the whole Slovak Republic.

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