



**Doctoral School of Social
Communication**

SUMMARY OF THESES

Orsolya Katalin Szépe

**Communication in hospices and in the process of dying
The place of hospices in our time, in public discourse and in the way life is
seen by generation Y**

Ph.D Thesis

Consultant:

Sándor Bordás, Ph.D.

Lecturer

Budapest, 2015

Institute of Behavioural Sciences and Communication Theory

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1. Literature review and the reasons for the choice of the topic

The culture of death and dying is extremely problematic and controversial in our time. The situation is much better with the start of human life: expecting and receiving the newborn is a relatively well-worked-out area of human existence with its well-established norms, activities, institutions and a network of provisions. The same cannot be said about departure, farewell and dying. No doubt, in the past hundred years there has been a lot of progress in medical care for those suffering from serious, incurable illnesses and the range of options for their treatment has significantly expanded. Tanatology¹, palliative care², has by now become an accepted area of academia. However, a holistic approach to the care of those who suffer from incurable diseases and the hospice institutions set up to implement this approach are less well-known and do not have an important position in public discourse.

My interest in this topic started when I was affected by it in my family. In that depressing situation, I had to confront a number of questions, to which I was seeking answers in vain: Why is it that the end of human life, which used to be experienced as a natural process, has by now become a phenomenon associated with only fear, dread and pain? Why are we often forced to deny the dying their natural need to depart from life in dignity and among their loved ones, rather than alone and defenceless? I was trying to find out what people think about the fact that dying has become a taboo topic, about the real needs of those suffering from serious illnesses and dying and about the fact that those dying themselves often feel that it is not appropriate or they should not talk openly about their real wishes.

The attitude of young people to illness, dying and death is particularly problematic. Talking to students in higher education, I have often noticed that they are divided in their attitudes to the topic of death and fatal illnesses. Most of them find the topic strange and uncomfortable and cut the conversation short. However, others become engaged in the discussion very enthusiastically. I wanted to find out whether those young people who are more ready to talk about the topic know more about the holistic care model characteristic of the hospice institutions or whether their way of thinking about the topic is different from those who are averse to discussing it.

¹ A discipline dealing with death.

² A range of supportive care to ease the symptoms of the terminally ill.

By using questionnaires, one of the aims of the dissertation is to map out, analyse, and describe the attitude of young people to the topic of death and dying, to summarise their views and experiences regarding the terminally ill and to portray their knowledge of the institutional system of hospices and their approach to the dying. The target group of the research was the age group of 18-25, with particular regard to higher education students.

It was also my aim to touch upon – even if not in detail - several new phenomena and attempts for solution to the problem and some new approaches regarding the topic of death, dying and bereavement. These include the Internet bereavement portals, the role of volunteers in hospices, the social discourse on euthanasia and the Marie de Hennezel care programme.

1.1. Aims and new knowledge

The focal point of my research is to identify the specific features of contemporary social attitudes – with particular regard to the views of young people – to serious illnesses, dying and death; and the kind of solution offered by the hospice service to these serious problems. I hope that the analysis - *the typology and systematic review (classification)* - of these attitudes will provide a useful contribution to the achievements of tanatology research.

2. Research methods

In terms of methodology, my research can be divided into two parts:

In the first part, I present the quantitative survey I conducted among students who study economic, technical and social science subjects at higher education institutions in Budapest. I used a questionnaire designed by myself and group sampling. To create the sample, I chose one year 1 group of a course at each of the selected four universities and two higher education colleges. I asked all students in those groups to fill in the printed questionnaires in person in the 2013-2014 academic year. Of these students, 600 filled in the questionnaire, which included 19 questions. I have analysed the answers, which included 48 variables in total, by using the SPSS statistical programme.

The following higher education institutions took part in the research:

- Budapest University of Technology and Economics (N=127)
- Corvinus University (N=27)
- Eötvös Loránd University (N=65)
- Károli Gáspár University (N=50)

- Budapest Business School (N=176)
- Budapest College of Management (N=154)

Breakdown by sex: 55% female and 45% male. Breakdown by age groups: 43% under 20, 46% between 20-23 and 11% over 24.

In the second part, I present the results of *qualitative research*. I conducted interviews in two focus groups:

1. Focus group: with the participation of those students who, in the questionnaire used in the quantitative research, volunteered for a face-to-face conversation. Of the respondents, 30 students opted for this. After I contacted them, 11 of them (aged 19-26) took part in the focus group interview.

The primary aim of this investigation was to have a more detailed discussion about the responses in the questionnaire and to reach a deeper understanding of their attitudes to - and views on - death, dying and serious illnesses through a personal conversation.

2. Focus group: 7 people who work in hospices (1 doctor, 2 nurses, 3 physiotherapists, 1 volunteer) who have to face the issue of dying in the course of their everyday work.

I felt it necessary to compare the hospice workers experiences with the knowledge and understanding of the young people. I wanted to find out the extent to which hospice workers aware of the opinion of “non-professional” people, what they believe young people know about the hospice service, what they think about the needs of their patients, how they solve their everyday problems and to what extent they view these problems as global problems. I analysed the two focus group interviews individually as well as in comparison with one another.

3. Research results

3.1 Hypotheses

Before the quantitative and qualitative research, I formulated 6 main groups of questions and hypotheses:

1. Research question: To what extent is the institution of the hospice known by young people? To what extent does the awareness of the hospice service depend on gender, age, area of study and the value system of young people? Is the awareness of hospice service in correlation with the views of respondents on the basic needs of those dying?

H1: My preliminary expectation was that: The availability of hospice service is not sufficiently known among young people, or their knowledge on this is often incorrect. There are significant differences in their understanding depending on their gender, age and area of study. Their knowledge on the hospice institutions also depends on their views on the basic needs of the patients who are dying.

2. Research question: According to young people, what is the most appropriate place for seriously ill patients a few weeks before their death: their own home, a hospital or perhaps a different place.

H2: According to my hypotheses, the responding young people – despite contemporary social attitudes - would consider death at home, that is, among members of the family and relatives, the most appropriate.

3. Research question: How much do young people talk about death and dying at home, in a family environment? Do those young people who have heard about hospice talk more about these issues?

H3: As the two-generation family model, where only parents and their children live together, is becoming more and more common, one would assume that children/young people seldom have direct experience of the life stage of serious illness and death, therefore death and dying are typically not topics of discussion in the family.

4. Research question: What do young respondents think the most fundamental and vital needs of a patient in a critical condition in the last few weeks of their life are? Do they see any similarity between the basic needs of a woman in labour and of those people who are dying?

H4: I hypothesized that the respondents would consider painkilling and medical care to be the most fundamental needs of such patients, while there would be no significant differences in the priority order of these needs among the respondents. There would be a significant difference between the young people's attitude and response to the two life situations (giving birth and dying), since these days people handle birth and giving birth more naturally than problems related to serious illness and dying.

5. Research question: How far do young respondents think the doctors should carry on treating people with incurable diseases?

H5: I expected that, in the case of patients with incurable diseases, young people would consider the needs of patients to enjoy priority over the doctors' unconditional intention to cure a patient and extend the duration of their lives. They would consider the opinion of doctors, family members or legal regulations to be of secondary or tertiary importance.

6. Research question: Are there any differences between the views of higher education students and hospice workers on the 5 groups of questions above?

H6: My hypothesis was that there is a fundamental difference between the attitudes of students and hospice workers to dying and death, as hospice workers related to those dying with less inhibition, more directly and more naturally than students.

3.2 The structure of the dissertation

In the first part of the dissertation, following conceptualisation³, I discuss the theoretical background of thanatology. I present the topic of death and dying from the perspective of cultural anthropology, psychology and social communication. First, by looking at the topic from various academic aspects, I will review, based on Philippe Ariès's book (1987), the changes in attitudes to death in the course of history. Then I will discuss the attitude of modern and postmodern societies to death, also outlining the typical structural changes in families in the 20th and 21st centuries and briefly summarising the characteristics of the so-called Y generation (Gorer, 1955; Rosengren, 1994; Noëlle - Neumann, 1980. In Dieter et al., 1992; Hegedűs, 2006; Tari, 2010). Talking about the topic of death, it is almost impossible to avoid the question of euthanasia. Chapter 2.3 outlines the terminology of euthanasia and eutelia (good death) and the relevant social and legal issues (Zubek, 2011; Bitó, 2005). An important part of the next chapter is a review of the psychological aspects of dying, based on the work of US psychiatrist Elisabeth Kübler-Ross (Kübler-Ross, 1980). This chapter also outlines the latest social efforts on processing the problems of death and bereavement. One of the possible solutions for this problem is the hospice movement, the key features and principles are outlined in Chapter 3 (Saunders, 1959; Hegedűs, 2006; Polcz, 1993). The chapter describes the organizational and legal background of the hospice – palliative care services. This chapter also includes an international review, comparing public awareness of the hospice services in various countries, based on various research reports (Hegedűs, Munk, 2015; McIlpatrick, 2014). The chapter also discusses volunteering, its importance, and more precisely the experience

³ The section on conceptualisation defines the following terms: death, dying, palliative care, human dignity, quality of life, hospice service.

I gained while completing a training course for volunteers at the Budapest Hospice house (Hungarian Hospice Foundation, 2014).

Chapter 4 includes the results of the questionnaire-based survey, where I analyse the responses given by 600 higher education students. This is followed by Chapter 5, where I interpret the results of interviews conducted with students and hospice workers. In Chapter 6, I summarise my results and outline the most important conclusions, according to the novelty of the topic examined.

3.3 The summary of results

H1: My preliminary expectation was that the availability of hospice service is not sufficiently known among young people, or their knowledge on this is often incorrect, and that there are significant differences in their understanding depending on their gender, age and area of study. Their knowledge on the hospice institutions also depends on their views on the basic needs of the patients who are dying.

The results of my primary research have confirmed my hypothesis that the care system offered by hospice organizations is not sufficiently known in various social strata and in various age groups. *Only 23% of the 600 respondents in higher education were aware of hospice, while 77% had not heard about it.* Those who had heard about the hospice service often had incomplete or incorrect information about it. Regarding awareness of the hospice care system, there are significant differences between respondents depending on age, gender and area of study by students. A higher proportion of older or female students and those who study social sciences have more thorough and more precise knowledge.

I have also found significant connections between the awareness of hospice and students' views on the basic needs of dying patients regarding the following needs:

- *Positive attitude to life:* those who are aware of hospice ranked positive attitude to life higher than other needs of patients.
- *Appropriate medical care:* Those who are aware of hospice consider medical care of medium importance only, while those who do not know about hospice consider this need very important or not important at all.
- *Religious support:* Those who consider religious support extremely important include a much higher proportion of students who are aware of hospice.

The results clearly show a difference between the attitudes of the two genders towards dying and death in their responses to most questions on the basic needs of those dying.

H2: According to my hypotheses, the responding young people – despite contemporary social attitudes - would consider death at home, that is, among members of the family and relatives, the most appropriate.

The results have confirmed my preliminary expectations: Close to 46% of young people think that those dying should spend their last few weeks “*at home, in the family*”, 25.8% consider being “*not at home but with the family*”, 15.6% consider “*at home with home care support*” and only 12.8% consider *hospital* to be the most appropriate place for those dying. The student focus group interview has refined the results of the questionnaire-based research. It has been repeatedly said that, although the moral norms of society expects care for the patients at home according to their physical and spiritual needs, the relatives, despite these expectations, in reality, are often forced to resort to other solutions because of their difficult family circumstances. The examination of the questionnaire’s results by gender shows that male respondents clearly regard home environment as the most important need, while female students consider the presence of the family more important in choosing the place for those dying. In is unambiguous in the case of both sexes that the respondents consider care in family circle the best for those dying.

Both focus group interviews – with the students and the hospice workers – revealed that, according to their opinion, *neither relatives, nor doctors are prepared enough for the care of those dying; they are afraid of taking responsibility and are desperately hopeful about the recovery of the patient.*

The questionnaire results may mean that, in the view of young people, there is no single correct solution for the place of death or dying, that they have no clearly formulated opinion on this, and that they think the most appropriate place should depend on the circumstances. The students’ views are often divided on this question; they often think that relatives should be expected to take into consideration the wish of those dying to the utmost degree. However, hospice workers – because of their empathy and experiences – show much more understanding of the real options families have.

H3: As the two-generation family model, where only parents and their children live together, is becoming more and more common, one would assume that children/young people seldom have direct experience of the life stage of serious illness and death, therefore death and dying are typically not topics of discussion in the family.

Investigating the third hypothesis, the results show that *almost three-quarters of the respondents talked about death in the family, though only in connection with an immediate event; 11% of them have never talked about it, while 14% have talked about it a lot*. It means that young people do not really have the opportunity to get familiar with the topic, get prepared for it, so that they know how to behave if they become directly affected by it in a concrete situation.

Talking about personal experiences during the focus group interviews, students often said that they were unable to get prepared for the death of a relative during the stage of dying, there was no mention of the possibility of death and it made the grieving process more difficult for them. During the focus group interview with hospice workers, the family members' averting mechanism was often mentioned. This could be the result of unpreparedness and the fact that death has become a taboo subject.

No significant connection could be detected between the awareness of the hospice service and the frequency of talking about death. There was no connection between the respondents' family type in their childhood and their awareness of the hospice either. The most common family type was the nuclear family (55.1%), which supports my hypothesis that these days young people face the question of illnesses and death less frequently than before. Although the hospice service has almost reached nationwide coverage, based on the responses, it appears that it is not sufficiently known among patients and their relatives.

H4: According to my hypothesis, the respondents would consider *painkilling* and *medical care* to be the most fundamental needs of such patients, while there would be no significant differences in the priority order of these needs among the respondents. There would be a significant difference between the young people's attitude and response to the two life situations (giving birth and dying), since these days people handle birth and giving birth more naturally than problems related to serious illness and dying.

One of the central points of this thesis is to offer a more precise definition of the preservation of the human dignity of those dying and human dignity that can be harmonized with the needs of seriously ill patients. The respondents had to assess the importance of the options listed (the basic needs of the patients). I compiled the options on the basis of the basic principles of the hospice service and other thanatology publications. (Kübler-Ross, 1980; Hegedűs 2006; Polcz 1993; Magyar Hospice Alapítvány 2014)

According to the responses given to the questionnaire regarding the basic needs of the dying, *respect for human dignity is the most important need of the dying patient*. It is immediately followed by *the presence of the family or close relatives*. *Medical care, painkilling* and *bodily needs* only follow these. The respondents also considered direct emotional support for family members very important. However, *during the focus group interviews*, both the students and the hospice workers laid emphasis on *painkilling*. Human dignity as a basic need only followed this. Asked specifically about human dignity, both groups voiced the opinion that patients must be treated as human beings till the last moments in their lives and should be treated in the same way as patients who are not dying or as they were treated before their illness.

I compared the respondents' opinion about the most important needs of patients suffering from serious or fatal diseases in the last few weeks of their lives with questions on giving birth, which were lead-in questions in the questionnaire and which was only a secondary topic of my research. When considering the needs of people in the two different life situations, there was a fundamental difference regarding painkilling, religious support and the need that the patient/he woman giving birth should not be left alone. All three of these basic needs were considered to be more important in the life situation of dying.

To sum up the two life situations' cross-table results – in accordance with my predictions – we can find significant differences regarding the importance of painkilling and the extent to which a woman in labour and a dying person may need “*not to be alone/never to be left alone*”. There were also differences regarding spiritual needs. It can be assumed that young people have little experience in either of the two life situations, but they perhaps they have more knowledge about the life situation of birth/giving birth and perhaps they talk more about it. However, irrespective of the life situations, most young people attributed high values to all the comparable basic needs.

H5: I expected that, in the case of patients with incurable diseases, young people would consider the needs of patients to enjoy priority over the doctors' unconditional intention to cure a patient and extend the duration of their lives. They would consider the opinion of doctors, family members or legal regulations to be of secondary or tertiary importance.

My hypothesis has essentially been proven right regarding my question on how long doctors should deal exclusively with curing a very seriously ill but still conscious patient. *Patients' needs are the most important* for the respondents (34.4%), but many of them think that, as far as there is *hope for recovery*, doctors must try to cure them. The

respondents considered hope for recovery almost as important as the needs of the patient, although the question was about patients with incurable diseases. Trust in medical science appears to be unshakable for the time being, since many believe that doctors are able to cure even people who suffer from incurable diseases. Owing to endless pain and suffering, patient needs are often not clear; they change and often contradictory. As a result of this, the patient's relatives do not understand or do not take seriously the dying patient's wish for no more treatment. This is where the question of euthanasia or eutelia, which are at the moment banned by law in most countries, can be raised.

H6: My hypothesis was that there is a fundamental difference between the attitudes of students and hospice workers to dying and death, as hospice workers relate to those dying with less inhibition, more directly and more naturally than students.

This difference can clearly be demonstrated by the results of the focus group interviews. Both groups considered it important to give an opportunity for the dying to die in dignity, but the hospice workers formulated the meaning of death in human dignity in a much more differentiated way and have a more natural attitude to dying, than the students.

The most salient difference between the focus group interviews was the atmosphere of the interviews. While the students often became emotional and afterwards they stayed gloomy and serious, those working in hospices spoke about their own experiences and stories about those who were dying in a positive mood and cheerfully. Their opinions regarding the answers to the groups of questions were essentially not different. They agreed on that the patients' interests must be taken into consideration to the maximum extent, but the hospice workers were much more tolerant regarding the family members' and relatives' ability to care for the patients. Of the students, those participated voluntarily in the interviews, who in the first place considered this topic closer to them – they might have even be personally affected by it – or those who were not as averse to discussing it as their peers.

3.4 Conclusions, suggestions

In conclusion, it can be said that the students' attitude to death and dying is ambivalent and uncertain, and that their knowledge about hospice services is often incomplete. Only less than one-quarter of the higher education student respondents had heard about the hospice service. True, there are also facts which can be seen positive: Half of the young

people consider home and family environment to be the most suitable place for dying;, while two-thirds consider the presence and support of the family to be particularly important in the past weeks of the patient. However, they also expressed the fundamental requirement that patients in the last phase of their lives, those who are dying, should be treated according to their needs and that they should not be left to hospital treatment only. In their view, it is important that the patients spend the last stage in their lives by preserving their human dignity. These views, although not formulated precisely or in detail, are close to the holistic approach of the hospice service.

One of the most important conclusions of this research is that the young generation also appears to see dying and the needs of the dying in a holistic way, and that they think similarly to those who work in hospices. However, as they do not get properly prepared for the problems of dying, death and illnesses, they are unable to face the issues of death and dying in accordance with their views. The young people clearly expressed the need to influence public opinion about death and dying, to break taboos and prepare the society for these issues.

There are a lot of social initiatives in this area with more and more success. The Charon thanatológiai Review (Kharon Thanatológiai Szemle), published since 1997 and articles published in a number of other publications play an important role in shaping public opinion on this issue. The “Magyar Hospice-Palliative Egyesület” [Hungarian Hospice-Palliative Association] has set up a Facebook site with continuously refreshed content, which has also touched young people. Public service, which is compulsory in secondary schools since 2016, requires every student to carry out 50 hours of socially useful activity that benefits a community. Various hospice organisations can take part, and increasingly do take part, in the programme. These experiences show that the hospice service is becoming more and more widely known. At a Corvinus University course entitled ‘Communication Problems’, which can be attended by students of any faculty, there are lectures about end-of-life communication problems related to dying, illness and death.

However, all this is not enough, if a holistic approach to dying is not established at a very young age. The aim of the “Narciszprogram” (‘The Daffodil Programme’) within the hospice is to support this endeavor. Its aim is to achieve that children, as early as at nursery age, should get experience that shows them that death is part of life and that everyone has the need to be able to live in dignity till their last moment.

Naturally, education and attitude-shaping is significantly influenced by socialization in the family and cultural differences. The “Z” generation already lives in the era of media, smart phones and computers. They could be reached via these means. A good example for this is the above-mentioned Facebook initiative. It would be important to achieve, that young people pass on their experiences and opinions to those even younger, that in schools they can discuss dying so that it cannot be treated as a taboo subject in education. Those who have more such experience could tell their own stories, which could often be painful and sad, but also useful and moving. Discussing eutelia in this dissertation, there was a mention of what Bitó calls “trained helpers of passing” (in some form, the modern phrase “coach” can also be used to describe them). There is a need for an institution system, in which professionally prepared “trained helpers of passing”, who are experienced in every area of care for those dying would deal with both those who are dying and their family members. They would prepare them for death or care for those dying and they would help them accept what cannot be changed. The methodology of palliative care should be prepared and put into an institutional framework and, by doing so, a new culture of care for those dying could also be created.

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