

BABEŞ-BOLYAI UNIVERSITY CLUJ-NAPOCA  
FACULTY OF SOCIOLOGY AND SOCIAL WORK

**The incurable and terminal illness – attitudes  
and assistance in Romania of today**

**PhD Thesis**

**Summary**

PhD candidate: **Görög Ileana**

Scientific coordinator: University professor **Roth-Szamosközi Maria PhD**

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**Key words:** illness, experience, attitude, mentality, communication, awareness, knowledge, incurable illness, advanced stage, terminal stage, palliative care, death, loss, family, society, faith, narrative, focused interview, key caregiver, care, support

**Part I. “Theoretical background”** of the work shows the current knowledge in the specialty literature, defining the evolution of mentality and attitude regarding incurable illness, death and loss.

Attitudes toward death and incurable illness have changed significantly over the historical evolution of society. Macro and micro social changes of the transition process from traditional societies to modern, industrial society had an impact on the conception of life and death. Progress of science and society instead to lead to a better understanding and acceptance of the inevitable end, have contributed to its removal from its natural, familiar /homely environment. Death has become “more macabre, lonelier, more mechanized and more dehumanized”, affirm Kübler-Ross at the end of the 60’s. Society empowerment, development of medicine and medical technology has led to a more pronounced sharing of the end of life. (Kübler-Ross, 1969, Arriès, 1985, Polcz , 1989, Field and Cassel, 1997, Hennezel, 1997, Olson, 1997, Corr, 1998, Kárpáty, 2002). Death is more removed from social life, along with the relocation of the place of death from the house in hospitals. Rites of separation in the process of accompanying the patient until the last moment by loved ones have lost their value, and death is seen as a failure of doctors to heal the sick (Crăciun , 2006, Bertand 2008). Among the factors that contributed to changing attitudes towards death, Bertrand calls also the withdrawal of western religions and secular advancement in modern societies.

Sub-chapter 1.2 deals with changes in family structure and functions, with references to authors who have treated this subject: Mihăilescu, 1993, Stănciulescu, 1997, Mitrofan and Ciupercă, 1998, Ghebrea, 2003, Băran-Pescaru, 2004, Iluț, 2005. Transition from extended family to modern nuclear family, in which both spouses are working / are bringers of income, in Romania is a slower process than in western societies, but , transformation passes on how the families can fulfill their various functions. One of the functions adversely affected is also the function of solidarity, of childcare, sick care and elder people care. There is a growing variety of types of families in Romania that we have to take account. In the present research, we applied the definition of E. Stănciulescu (1997, p. 26) that family is the "social unit consisting of adults and children, which have natural-daughter relationships (blood relationships) or social relationships».

Still in this part of the thesis are presented the role of environmental factors, the theory of social ecology of Urie Bronfenbrenner (1979), and a number of particular situations that may affect the family adaptation to the changes triggered by serious illness or death of one of the members. Illness and loss have a different impact depending on the family life cycles, family types, on the role in the family of the person affected by illness and of the socio-economic circumstances of the family.

Facing a life threatening illness brings in the spotlight existential and spiritual aspects. Cultural-spiritual factors, with particular role in relation towards illness, suffering and death, are presented in sub-chapter 1.3. Knowledge of representations, beliefs, specific concerns of different cultural backgrounds is of great importance for professionals that assist the dying persons and those in their entourage (Twycross, 1999, Mitrofan and Buzducea, 1999). Listed papers shows the role and significance of faith in Romania regarding the individual and collective reporting to death (Kligman, 1998) and the Orthodox faith perspective on the theme of illness and imminent death (Larchet , 2006, Stancu,2007, Apostolu, 2007). Are also discussed issues related to traditional folk conception (Suciu, 1998, Kunt, 2003), importance of rituals (Collins and Coltrane, 1995, Marchall, 2007) and of spiritual values in the crucial moments of life (Walsh, King, Jones, Tookman and Blizard, 2002, Hinshaw, 2002, Chiu and colleagues, 2004). Definition of spirituality is given by citing Morgan (2003). As a model for assessing the spiritual history of the person is presented the technique proposed by C. Puchalski (2000), and as a model for intervention to alleviate existential suffering, is presented the “dignity therapy” developed by Chochinov (2005, 2006).

**Chapter 2** - Support for incurable patients and their families - brings together references to works that deal with sickness behavior, communication of professionals with the patient and its relatives, psychosocial aspects of care for incurable patients. It is presented the contribution of social sciences in the last four decades to change how illness is viewed, by focusing attention on the sick person experiences (Charmaz, 1999, Kulcsár 1998). The concept of “Death Pathway” is linked with the name of Glaser and Strauss (1965) and Murray, Kendall, Boyd and Sheikh (2005) are cited for the study of the peculiarity of death trajectory to the patients suffering of cancer. The concept of “Illness Trajectory” is developed on the basis of “Death Trajectory” concept and surprise the illness running together with its social issues, with its specific interactions between the sick person and those who come in contact in his effort to rebuild the health (Kelly, 2008). **Sub-chapter 2.2** is assigned to the role of communication between the incurable patient, medical staff and patient relatives. Principles of how to break bad news are presented with references to works of P. Kaye (2005) and R.Twycross (1999). Kaye's idea is underlined that communication can not be avoided, and lack of honest communication creates difficulties in relationships and resentments in the relationships that should assist the patient. But equally important is the good management of information, to provide as much information as desired by the patient and his family, and when they ask for it (Olson, 1997). Inadequate communication may traumatize the patients and their relatives, may affect their ability to

participate in decisions, and generally, their ability to face with the illness (Field and Cassel, 1997). Huber and Gibson (1990) have called suggestive “The 10-Mile Bridge of Mourning “the period which lasts from the first bad news about terminal illness until the regain of the ability to continue the life after losing the beloved person. The role of professionals in supporting honest communication between the patient and his relatives is mentioned by Olson, 1997, Stedeford, 1994 and Hennezel, 1997.

The **sub-chapter 2.3** “Psychosocial aspects of incurable patients care” mentions works that signals attention deficiencies in social and human issues in the biomedical health services. Many authors report that health professionals avoid communication with the incurable patient (Buda, 1994, Hárđi, 1975, Twycross, 1999, Walters, 2004, Bogdan, 2008). R. Twycross, 1999, Bogdan 2008, Stewart and collaborators, 2000, explain the barriers encountered by medical personnel in caring for dying patients, among other things, the lack of adequate training. Iamandescu (2003) proposes a strategy to consider the patient's psychological state besides the treatment, and Weissman, Ambuel and Hallenbeck (2000) recommend analyzing and processing Specific and professional experiences of losses.

**Chapter 3** presents the purpose and basic principles of palliative care and hospice services, which brought a radical change to the incurable and terminal patients care (Connor, 1998, Clark, 2000, Wright et al., 2006, Walters, 2004). Initiation of modern hospice services is tied to the name of Dame Cicely Saunders, to her years of work at the St Christopher Hospital in London, England, during the years of 60's. The first U.S. hospice was established in 1974. Palliative care and their basic principles are defined (WHO, 2002, 2010), are presented provisions of the Declaration signed in Barcelona in 1995 by the WHO Program on Cancer Care and Palliative Care and by the European Association for Palliative Care (The Barcelona Declaration on Palliative Care, 1995) and the Recommendations of the Council of Ministers of Europe (Rec 24(2003), “Pathway for Patients and Families Facing Terminal Illness”, used by National Hospice and Palliative Care Organization (NHPCO) from America. Importance of relatives involvement in patient care and of support provided to families is sustained by Steinhauser et al., 2000, Teno et al., 2001, Heyland et al., 2006 and Rietjens et al. 2006, who studied what patients and relatives consider to be the most important elements of quality of care received at the end of life. A general conclusion was that, care may not be reduced to pain control; besides effective treatment of physical ailments, patients are waiting to be understood their emotions, to be supported in their relationships, and to be taken into consideration their spiritual fights.

**Sub-chapter 3.1** presents some of the questions about the prospects and directions of development of the hospice movement in the future (Clark, 2000), and the next sub-chapter 3.2., presents the history and the evolution of services for incurable patients in Romania. The Hospice Movement has grown and gained weight in Europe in last decades, in response to the increase in cancer incidence and average life expectancy, including among incurable patients. The concept

was accepted in the countries of Western Europe in the late of the 80's and in Eastern Europe after 1990. Romania is included among the countries of Eastern Europe which could agree the hospice philosophy since 1989, going through a relatively slow but progressive course until now. Palliative care and hospice services in Romania have been introduced gradually since 1990 and extended through the sustained effort of some promoters, charitable foundations, professional associations and public figures in the medical world, mainly with the support of partners from countries with experience in these areas. 1992 marks the beginning of several initiatives for palliative services in several places in the country. In January was founded at the Berceni Hospital (now St.Luke Hospital) in the chief town the Romanian Association for Palliative Care Development (ARDIP), in March was opened a hospice for children suffering from AIDS in Cernavoda, financed by Romanian Children's Aid Foundation (now Children in Distress), in April 1992 was founded the Roman- English Hospice "Casa Sperantei" in Brasov city. There are presented in more details, moments of the development of hospice services, along with educational programs and scientific events organized for professionals in the country and in the countries of South Eastern Europe through the Palliative Medicine Study Center, belonging to Foundation Hospice "Casa Sperantei" from Braşov. To support the development of hospice and palliative care services and institutions / sections, the National Coalition for Palliative Care in Romania was founded. Also a project was initiated for centralized data collection (Minimum Data Set) regarding quantitative and qualitative indicators of palliative care providers, members of the coalition (a total of 17 palliative care services in 11 counties) (source: Annual Report 2008, Hospice "Casa Speranței"). It can be ascertained the increasing interest regarding the situation of patients with incurable illness in Romania manifested also by representatives from non-medical areas. The psychosocial and spiritual aspects of incurable and end-stage illness are increasingly frequent topic of master and doctoral theses and publications (Skolka, 2004, Susan, 2004, Vaida, 2005, Crăciun, 2006, Dumitrescu, 2006). In 2008, the electronic journal of palliative care "Paliatia" was created, to publish quarterly writings of palliative care ("Paliatia", 2010).

**Chapter 4** presents briefly bioethical aspects of complex situations that may occur in case of end of life care. Cited authors: Breslin and colleagues (2005), Astărăstoiaie and Trif (1998), Trif, Astărăstoiaie and Cocora (2002).

## **Part II. Empirical Researches**

**Chapter 5.** This part of the thesis meets the objectives, the methodology and the results of three studies: 1.) experiences, concepts and beliefs related to incurable illness and death in our society today (chapter 6), 2) experience of families caring / have cared a serious sick relative dependent of care (chapter 7) and 3) Specific experience of patients in dealing with an incurable illness (chapter 8). The theme of death being a sensitive topic when it has specific implications, a great part of information on which the research is developed, have been gathered from life situations, by observing, facilitating and recording events and information. Situational collected data,

through observation, listening and record stories of assisted patients, were supplemented by more rigorous techniques: semi-structured interview, analysis and processing of collected narratives, secondary analysis of data from the medical records and of the results of a population survey. The studies are focused on four aspects of the advanced stage and terminal stage of the incurable illness: - communication / knowledge of diagnostic and prognosis; - care of the patient at home in advanced and terminal stage of illness, - patient and family needs; -impact of the illness : aspects of individual and of family group development

I watched as independent variables: - individual variables: age, gender, educational level, self-appreciated faith and marital status of persons from the research groups - family variables: key career, current family structure, descendants seated at geographic distance from the sick person, and social variables: the urban-rural population.

The questions I looked for an answer by the present research were: a) in Romania, today, cancer diagnosis and imminent death of the patient are avoided subjects? b) How the family faces to the situation, if one of its members needs continue care in the advanced stage of cancer? c) characteristic evolution of cancer contribute to the patient preparation and to preparation of his relatives for the inevitable end? d) There is specific development in the process of confrontation with a illness that causes many sufferings? e) Contribute faith in a better comfort of patients? f) The palliative care services in Romania for nearly 20 years are reflected in knowing these services by the population?

The research combines quantitative and qualitative methods. The used methods were: a) population survey data's secondary analysis b) retrospective analysis of medical records of patients who received palliative care through hospice, c) Analysis of narratives and focused semi-structured interviews with patients being in hospice care in advanced and terminal stage of their illness. (Figure 1).



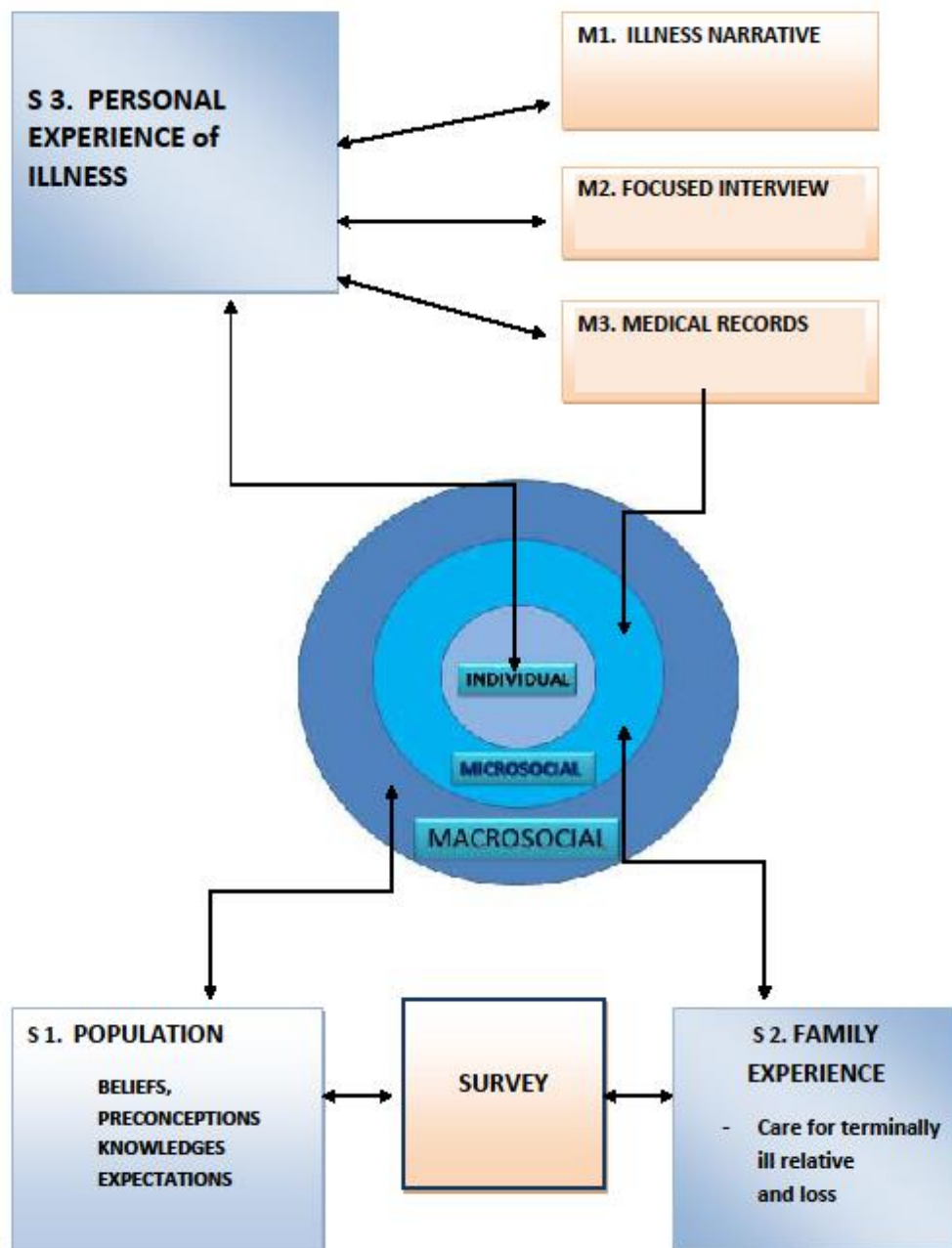


Fig.1. The structure of research: Studies (S), objectifs and methods (M)

**Chapter 6** of the thesis shows the society's approach of terminal illness and death. The purpose of this component is to highlight concepts, beliefs, experiences and knowledge existing in the current Romanian society regarding incurable illness and services for terminally ill patients, in order to better understand the socio-cultural context influences of the mentality and attitude of those who are facing a life threatening illness.

As bibliographic guides I chose articles of the last years, focused on the perceptions of incurable illness and death in modern societies, which signals first the important mentality changes concerning the incurable illness, but also the need to improve services for patients being at the end of their life and for their relatives (Defanti, 2010, Viola, Leven and Le Pere, 2009, Claxton-Oldfield, Gosselin and Claxton-Oldfield, 2009, Kaldijan, Curtis Shinkunas, and Cannon, 2008, Csikos, Albanese, Busa, Nagy and Radwany, 2008) The specific study is based on secondary data analysis of a population survey commissioned by the Foundation Hospice "Casa Sperantei" and achieved in two stages (September 2007, March 2008) by a specialized company. In developing the two versions of the questionnaire used in the survey I have contributed to, near by Dr. Mosoiu Daniela, who has coordinated the research.<sup>1</sup> Questions were addressed face to face, by the company operators. Representative samples of the adult population of Romania (N = 1250) was elected by the electoral lists with stratification on urban / rural areas, age groups, gender, training level, with a margin of error of 2.3%.

For this chapter of the thesis, the relevant aspects of survey are: the desire to learn the diagnosis and prognosis of an incurable illness and the desire to communicate about them with loved ones depending on age, gender, education, urban-rural areas; the way the illness and suffering caused by this illness is seen; belief on life after death; population informing about the "hospice" and "palliative care" concepts. For processing the survey results, was used the SPSS program version 12..

**Chapter 7.** The family experience regarding the care for a relative in advanced stage of incurable terminal illness was analyzed based on relevant results from a population survey described in chapter 6. I used as bibliographic guides articles published in the last decades, which presents data on how relatives of the patient with incurable illness are affected (Davis-Ali, Chesler and Chesney, 1993, Hebert, Schulz, Copeland and Arnold, 2008, Sutherland, 2009). In the same time, since a large majority of patients preferred to end their life at home, I chose articles dealing with care problems at home and caregivers needs (Perrault, Fothergill-Bourbonnais and Fiset, in 2004, Chan Epstein, Reese and Chan, 2009).

Issues analyzed and discussed in this chapter are: family involvement in continues and final care of incurable patient / key caregivers, physical, emotional, relational and financial consequences of the period of intensive care on the patient's family.

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<sup>1</sup> Some of the results of the survey has been presented in a poster (Title "**Palliative care model and**

**Chapter 8.** Exploration of specific experience of the illness was achieved through qualitative studies: analysis of the narratives (N = 89) and of semi-structured focused interviews (N = 12) conducted with hospice patients, being in advanced respectively, in the terminal stage of a chronic illness. The investigated aspects were: situational awareness by the patient, communication about diagnosis and prognosis, needs and concerns of patients, key caregivers at home, and role of spirituality in the emotional comfort of the patient. My working assumption was that through the nature of its evolution, cancer cause a higher exposure to the experience of human life fragility, and that suffering people becomes awareness, during the numerous investigations, medical interventions and treatments, on the irreversibility of their situation.

As bibliographic guides regarding the study and description of attitudes in face of life threatening illness, I have presented the works of E. Kübler-Ross, 1969, Polcz A, 1989, R. Buckman, 1992, M. de Hennezel, 1997, Davis-Ali, 1997 and M. Renz, 2003.

#### **Study of patients' medical records that benefited of hospice care**

In this retrospective study, I collected and processed data from medical records on six months, regarding hospice patients died in the period from March to August 2009. Of all adult patients, I selected in particular those who have received at least two weeks of hospice care from "Casa Sperantei" teams. I excluded from the study patients who died just one day or several days after taking over, or did not want further hospice team intervention, because their medical records were very briefly completed. I identified 199 patients who received complex hospice services in this period. Specific and family data, communication about diagnosis and prognosis, self-appreciated faith, psycho-emotional needs and spiritual support, place of death were taken from medical records, respectively from the anamnesis and notes made during the care by the medical team members. For this, I prepared a questionnaire, presented in the annexes to the thesis. Data were centralized and processed with SPSS, version 12.

#### **Chapter 9. Summary of specific researches and conclusions**

##### **Knowing the diagnosis and prognosis**

The opening / the wish to receive or not full information about the illness, its possible treatments and its evolution, is studied both light the attitude of those who actually face with the incurable illness and benefits of hospice professionals care trained in breaking bad news, and the preferences expressed by the participants in a national survey.

Conclusions are drawn from comparative analysis of the results on knowing the diagnosis and prognosis by the patients in the investigated groups: group 1 - patients participants to the psycho-emotional support sessions (at the recommendation of the medical team, or at Specific request) who's narratives has been analyzed (N = 89) and group 2- patients cared by hospice teams that died in a period of six months (N = 199).

-Full knowledge of the information on the seriousness of the situation produces a greater burden (issue reported by Huber and Gibson, 1990, Kaye, 1996, Olson, 1997), but in the same time,

gives to the patient motivation to search for solutions and support. The percentage of patients who knows their diagnosis is 10% higher, and knowledge about diagnosis and prognosis brings a percentage with 7% higher in group 1, composed of persons recommended for counseling and those who have sought psycho-emotional support than in group 2, composed of all patients cared for by hospice within 6 months. (Table 1<sup>2</sup>)

**Table 1.** Knowing the diagnosis and prognosis by the patients in two groups

Knowing the diagnosis and prognosis	group 1 N=89	%	Group 2 N = 199	%
Knows the diagnosis and the prognosis	30	33,7	54	27,1
Knows only the diagnosis	37	41,6	63	31,7
Do not knows/denies both the diagnosis and the prognosis	14	15,7	41	20,6
Family avoids the patient informing on diagnosis	4	4,5	18	9
Family avoids the patient informing on	4	4,5	23	11,6

- In the case of persons of the first group, family members intercede in a smaller percentage (4.5%) to block the patient informing on both diagnosis and prognosis, compared to the percentages of 9% (blocking of diagnosis) and 11% (blocking of prognosis), for the patients in the second group.

- Among the individual-variables, the analysis of the results revealed a significant correlation between the patient's educational level and knowledge of diagnosis and prognosis. Thus, 62% of people with higher educational level of the 89 people group, fully knew both diagnosis and prognosis of the illness they are suffering, compared to 28% of those with elementary education and 30% of patients with secondary education. ( $\chi^2 = 20,900$ ,  $p = .050$ )

- In the first group, percentage of people who say that religion does not fulfill an important role in their lives is higher by 9%, compared to those who consider religion important. In the second group, the role of religion can not be assessed, because of high proportion lack of information about this issue (41%). (Table 2<sup>3</sup>)

**Table 2** Composition of groups from point of view of education and the importance given to faith

Education	N = 89	%	N=199	%	Religious creed and its importance	N = 89	%	N=199	%
8 yrs or less	32	36.0	75	37.7	Important	36	40.4	65	32.7

<sup>2</sup> Correspondant to table II/42 in the thesis

<sup>3</sup> Correspondant to table II/43 from the thesis

12 yrs	44	<b>49.4</b>	66	<b>33.2</b>	Not important	44	<b>49.4</b>	53	<b>26.6</b>
15-16 yrs or more	13	<b>14.6</b>	21	<b>10.6</b>	Not so important, but wishes to be visited by priest/pastor at the end of life	7	<b>7.9</b>	-	-
Lack of data	-	-	37	<b>18.6</b>	Lack of data	2	<b>2.2</b>	81	<b>40.7</b>

- For the other variables: age, gender and marital status of persons, no significant differences were found regardless the full knowledge of the illness situation by the patients in the studied groups. The following trends worth attention : people under 55 years are more frequently turning to emotional support and consequently are more open to discuss the illness and its consequences: they are present in a higher percentage, about 40%, in the first group (beneficiaries of psycho-emotional support), against only 27% in the second group (hospice patients cared within six months)) (Table 3<sup>4</sup>)

**Table 3** Group composition by age and gender criteria

Group 1	N=89	%		Group 2	N = 199	%	
<b>Age</b>							
<=35 ani	4	<b>4.5</b>	Media	<b>60.4</b>	<b>1</b>	.5	Media
36-55	31	<b>34.8</b>	SD	<b>14.2</b>	<b>49</b>	26.6	SD
56-69	28	<b>31.5</b>	Median	<b>64</b>	<b>75</b>	37.7	Median
>=70 ani	26	<b>29.2</b>	Range	<b>20 - 92</b>	<b>74</b>	37.2	Range
<b>Gender</b>							
Woman	49	<b>55</b>		<b>96</b>		48.2	
Man	40	<b>44.9</b>		<b>103</b>		51.8	

Differences in relation to marital status of patients can also be observed: the first group, the proportion of people without a partner (unmarried, divorced, widows) is of 43%, compared to somehow the smaller percentage of 39%.from the second group. Percentage of married people is higher in the second group with 7%. Situations of cohabitation without being married are more common with about 4% in the first group. Although not always rely on harmonious relationships, marriages seem to offer more safety for patients dependent on care (Table 4<sup>5</sup>).

<sup>4</sup> Correspondant to table Table II / 44 from the thesis

<sup>5</sup> Correspondant to table Table II/45 from the thesis

**Table 4** Group composition by marital status criteria

<b>Group 1</b>	<b>N=89</b>	<b>%</b>	<b>Group 2</b>	<b>N = 199</b>	<b>%</b>
Unmarried	5	<b>5.6</b>	Unmarried	8	<b>4.0</b>
Married	46	<b>51.7</b>	Married	117	<b>58.8</b>
Divorced	11	<b>12.4</b>	Divorced	22	<b>11.1</b>
Unmarried couple	5	<b>5.6</b>	Unmarried couple	4	<b>2.0</b>
Vidow	22	<b>24.7</b>	Vidow	47	<b>23.6</b>

Preferences expressed by the participants at the national survey regarding the desire to be informed about the diagnosis, the treatment, and the chances to be cured in the hypothetical situation of an incurable illness (Table 5<sup>6</sup>)

**Table 5** Preferences of participants in survey regarding the knowledge of diagnosis and prognosis

<b>Preference regarding the knowledge of diagnosis and prognosis</b>	<b>Survey N=1115</b>	<b>%</b>	<b>Group 1 N=89</b>	<b>%</b>	<b>Group 2 N = 199</b>	<b>%</b>
Knows the diagnosis/ and the prognosis/ Would prefer to know the dg. and prognosis.	488	<b>43.8</b>	30	33,7	54	27,1
Knows the diagnosis – do not knows or denies the prognosis/ Would like to know only the diagnosis and the treatment/ Would prefer that the word cancer not been pronounced	199	<b>17.8</b>	37	41,6	63	31,7
Don't knows or denies dg and prognosis. /would prefer to not know	309*	<b>27.7*</b>	14	15,7	41	20,6
Family blocks information on diagnosis/ Would prefer that a family member gets the information	66	<b>5.9</b>	4	4,5	18	9
Family blocks information on prognosis	-	-	4	4,5	23	11,6

“ Age” variable. Percentage of persons aged under 45 who say they would like to know the diagnosis and prognosis, is significantly higher ( $p = .001$ ) than that of people aged over 60, who either do not want to be informed ( $p = .001$ ), or prefer that a family member to be informed in their place, ( $p=.009$ ). Between those who do not want to learn the diagnosis, but the treatment, as prevalent age, are the persons of over 45 years ( $p = .005$ ).

<sup>6</sup> Correspondant to table Table II/46 in the thesis

“Educational level” variable. People with higher education at a rate of 72%-say they want to know in detail the diagnosis, the illness evolution and the chances of cure. The difference is significant compared to the responses percentage of individuals with eight classes (42%) and with high school (54%) (p=.000). Those with higher education level affirm in a significantly lower percentage (7.7%), that finding the diagnosis would lead to lose hope, compared with higher percentages of those with education up to eight classes (20,4%) and college (12%) (p=.001)

The analysis shows significant differences between rural-urban areas. Among people who affirm they want to know in detail the diagnosis and prognosis are, in a significantly higher percentage, the people of urban areas (58.2%), than those from rural areas (48%) (p =.000).

- 11.7% of urban respondents would prefer to receive only information on treatment, not the diagnosis, onto 16.9% of people in rural areas. (p =.001).

- A double percentage of people in rural areas (20.4%) affirm that “they would lose hope” if they learn the diagnosis, against people in urban areas (10.8%). (p =.000)

-The difference is smaller, but comes to stay as on the option about another family member to receive information: urban people would prefer this option in the percentage of 9.2%, and 12.7% of the people in rural areas (p =. 052)

Continuous patient home care, when the overwhelming majority of patients are in advanced stages of terminal illness, is provided only by the family. The fact is confirmed by the information selected from the patients who received hospice care (96%), and from the answers given by people participating in a population survey (95%) (table 6<sup>7</sup> and table 7<sup>8</sup>)

**Table 6** Caregiver(s) at home - Patients who received hospice care (N=199)

Caregiver/ Patient	Wife/husband	Daughter/ son	An other relative	Several members of the family	Paid caregiver	Elderly home	Shelter for Homeless
<b>Gender</b>	N ....%	N.....%	N.....%	N.....%	N.....%	N.....%	N.....%
Man	43.....21.6	10.....0.5	11....5.5	33...16.6	4 ..... 2	1.....0.5	1..... 0.5
Woman	22.....11.	18.....9.4	9.... 4.5	38... ..19.	8..... 4	- -	- -

**Table 7.** Main caregiver(s) of terminally ill person at home and other participants to care

Caregiver(s) care N=199	Group of patients in hospice care	%	Caregiver(s) respondants to survey (N=225 <sup>9</sup> )	%
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<sup>7</sup> Correspondant to table II/47 in the thesis

<sup>8</sup> Correspondant to table II/48 in the thesis

<sup>9</sup> Number of those participants who have had or has in care a terminally ill person

One relative alone	52.5	One relative alone	18.4
Several family members	35.6	Several family members	76.5
Paid caregiver by the family or the sick person	6	Paid caregiver by the family or the sick person	3.9
Institutional care or NGO aid	1	Institutional care or NGO aid	1.2

Regarding **the main person who provided care**: husband or wife provided alone the patient care at a rate of 33%, daughter or son (10%), other relative (10%) for the patients belonging to the group of persons assisted by the hospice, while, in case of the survey respondents, the percentage of people who had to face the task alone, the rate is lower (18%) and family relationship it is not specified. The total percentage of persons who faced alone the patients needs is nearly 3 times higher in the group of hospice patients - that might be due to the contribution of care and support provided by hospice staff, but also, there is the possibility that more relatives would apply to hospice care while being alone with the severely ill person. According to hospice patients cared for, a rate of 38% of them have children settled in other countries and other places in the country, and of them, very little return for the final part in caring.

**Participation of caregivers paid by the family** is insignificant: among the patients assisted by hospice, a rate of 6% has been totally or preponderant cared at home by an employed person and, according to the experience of the survey participants, the percentage is 4%.

**Deaths** were in most cases at home: 74%, according the data from the hospice records for six months, and 82%, according the population survey. Patient death occurred in the hospice inpatient unit, at a rate of 21% for those who received hospice care in the last stage of the illness, at their choice and / or at the choice of relatives. (Clarifying the patient desires is not always possible, either because of bad condition of the patient at the moment when the family turns to hospice care, either because of avoidance of discussion about the impending death, by the patients or relatives, favored by the absence of procedures to express final wishes. The anamnesis proposed by Feldman and Christensen (1997) is a good model for this.

The survey data indicates a significant difference between rural and urban areas about death at home, in the presence of the family. Although the number of responses on the experience of a death in the family is not large enough to be able to generalize the results, it worth noting as a problem still to be documented, that death occurs more frequently in these circumstances (almost always) in rural areas (92 %), compared with 75% in urban areas.

The survey reveals the fact that in Romania's urban areas, every fourth patient with terminal illness dies in a medical unit, in an intensive care unit (11%) or in another department of a hospital (14%). But we can not talk in Romania about life medical care in its final stage, which is a phenomenon of major proportion in the developed countries.



## **Needs and concerns of patients with incurable illness and of their relatives**

By their specific trajectory, cancer illness cause similar problems for people who suffer and their families. Narratives and focused semi-structured interviews with patients in advanced and terminal cancer illness reflect in the common themes, their effort of adaptation to the multiple physical, emotional, social and spiritual consequences of the illness.

The large share of reports on the illness in both narrative and interviews, show the intensity of the concerns of patients to understand and maintain control over the situation in which they are.

Acknowledging the gravity of the situation progresses at different people in different pace and intuition of the end of life approach is expressed rather by fear, allusions and story of dreams and visions than in direct communication. Oscillation between denial and awareness of the irreversible nature of the situation, the hope that something can be done, are also present in the advanced stage of illness, even if people have gone through many examinations, treatments and enlightening discussions with doctors. Supportive care takes account of /must respect the patient choice to receive so much information of how much they need and when they feel the need-principle stated also by Kaye, 1996, Field and Cassel, 1997, Abiven, 1997, Moşoiu, 2010.

Helplessness, dependence on others, worry of being burden to loved ones, are remembered by everyone as the heaviest burden: The dimensions of this burden can be better understood if we consider the percentage that care must be provided by one relative, most frequently by the husband / wife.

Ill people speak spontaneously less about family issues, emotional and spiritual issues, rather than on symptoms, treatments and medical interventions that they have passed. Semi-structured interview was a useful way to investigate patients 'concerns related to these issues, though they are important to understand patients' condition and reactions are rarely mentioned in discussions of patients with medical personnel.

Interviews highlight isolation of patients in advanced stage of illness. Social relationships of people with serious illness are restrained first because of limitations imposed by illness (mobility limitation, physical malaise and / or psychological discomfort), but also because of the reserves outside of family circle (neighbors, colleagues, friends).

Elder patients remain / prefer to be / almost exclusively with their close family members and younger patients keep relationship just with “good” friends which were supportive to them in difficult moments.

Hospice day-care center attendance is considered important by movable patients, because the meetings from there compensate their need for social contacts and are devoid of tensions caused by unauthorized or unreasonable attitude of people outdoors.

Material worries caused by illness are a common theme in interviews, but they reach critical dimensions, especially to people who had a precarious situation before the illness occurrence.

Narratives of patients and interviews state a continuous process of maturation of most people, expressed by seeking solutions to let its own affairs in order, through valued relationships with close people and by the effort to understand and integrate early life experiences.

Faith is the main source for maintaining hope at the interviewed patients: 11 of 12 people found comfort and support in religious creed, even though only four of them attended church before they get sick. Also, narratives of people accepting the approach of death reflect the comfort of religious beliefs and spiritual values.

Although spiritual care is part of the care provided by hospice, medical record records regarding the issue of faith to cared people, are defective: a quarter of records studied contain no mentions related to religion, and in 40% of it, is not specified how important is faith for the ill person. Palliative care medical staff should learn assessment techniques of spiritual / religious needs and integrate specific interventions into the appropriate patient care strategy, says Burton, 1998, Puchalski, 2000 and Walter, 2002.

National survey on the opinions concerning incurable illness and care of patients with incurable illness in our society signals the coexistence of different mentalities based on age, educational level of respondents and socio-cultural living area.

Differences between different cultural areas in sharing news of a serious illness with relatives are significant: Transilvania and Muntenia respondents would choose to tell about the illness to close people in a higher percentage of 33.5% and 33% compared to the percentage of Moldova (21.7%), and those of Bucharest (11.8%) ( $p = .005$ ).

One person of four would choose to talk about practical aspects of death and funeral with a priest if he is dying. A significantly higher percentage of people in Transilvania (37.2%) and Muntenia (30%) would discuss the final arrangements with a priest, against the percentage of Bucharest (7.1%) and even of Moldova (25%) ( $p = .027$ ).

Religious beliefs are expressed relatively low in population opinions related to sickness and death. In the 50% of respondents which affirm that the illness is about spiritual growth, are significantly more people with education up to 8th grade (54%), compared with 40% of respondents with higher education. ( $P = .000$ )

Share of those who see in suffering a spiritual growth path is significantly greater at the respondents from Moldova (57%) compared with 29% of the inhabitants of Bucharest ( $p = .000$ ). The answers of participants from Transilvania and Muntenia gather the overall average (49%).

Percentage of those responding that death is a passage to another existence is higher (43%) than that of people who think that everything ends with the death (36%). The share of people who say the answer is belief in the afterlife, is even so lower than the rate of 51% reported in the study of S. Gog.

Although faith is an important resource in adaptation to life threatening illness, religious assistance to the terminally ill is considered important only for 11% of the respondents to the survey. Most participants (70%) put on the first place the patient need for medicines and treatments to alleviate suffering. In a rate of 55% is important that patients referred to receive home visits from trained medical personnel and 35% of responses stated that the patient and relatives would need to be able to discuss concerns about the illness with a qualified person

**4. Knowing the concepts of “palliative care” and “hospice” by the population.** One result that first surprise, on the other hand signals the need for more effective measures for promotion, is the one that reflects lack of informing people about palliative care and hospice services. Although palliative care services are present in Romania for almost 20 years, the number of those who know the meaning of “palliative care” and “hospice” concepts is small, nor 1% according the survey.

The thesis is completed with several recommendations concerning directions for improving the care given to patients with incurable illness in the advanced and terminal stage, and their families.

Considering the pattern arising in the process of adaptation to illness of patients suffering of cancer, it is required an individualized information strategy and support from professionals that respects Specific choice and rhythm of each patient.

The burden of emotional and spiritual excitement that accompanies the final stage of life requires a more careful evaluation. Existential issues, spiritual suffering are not verbalized in routine communication with medical staff. It is required a protocol for assessing spiritual needs that respects our cultural specificity and could be applied by any of the care team. In Annex II / 8 of the thesis, I submit a proposal in this respect following the ideas of C. Puchalski (2000).

Spiritual values and faith are the main resources of the integration process at the end of life, and caused fears about the impending death confrontation. Opportunity to receive emotional and spiritual support is an important requirement for quality care. It remains to be studied to what extent would be welcome “the Dignity therapy “developed by M. Chochinov /2005, 2006) by patients who are in advanced and terminal stage of an incurable illness.

Finding ways to give more support to families caring for a seriously ill relative is required. Family members, as main responsible for the patient care, should continue to benefit of practical help through trained volunteers, guidance on the treatment to be applied at home, and emotional support (counseling, support groups).

Considering the continuous changes in the family structure, the greater mobility of the population, it is necessary to be found ways to assess the situation of home cared patients, to prevent serious deficiencies in care due to relatives inability to cope with complex tasks of continuous care or to the loneliness of the patient.

There are necessary more efficient ways and means of informing the population about palliative care and hospice services along with monitoring standards of care.