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A DIGNITY CENTERED MULTIDIMENSIONAL AND DYNAMIC MODEL OF QUALITY OF DEATH WITHIN TERMINAL STATE

Quantitative and qualitative analysis of answers issued by a sample of students (Special Education and Psychology departments) and a sample of nurses respectively

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> *„Dignity is socially constructed, individually perceived, embodied and relational”*
> *(Street and Kissane, 2001, p. 99)*

ABSTRACT. The concept of “death with dignity” represents a controversial concept, at the same time frequently used in legal settings, ethical, philosophical, literary, or death psychology domains. Renowned specialists of the field argue at the same time, that death with dignity is an artificial, useless, or even dangerous concept, respectively one of the most valuable psychological constructs with regard to quality palliative care. Several studies indicate that frequently, patients report that a loss of personal dignity leads to: hopelessness, depression, wish and even request of medical interventions for intentional shortening of life. Few studies make operational the concept of death with dignity as opposed to abundant literature on the concept of good death. In the current study, aside from a short theoretical framework of the topic, we analyze on one hand the answers given by groups of participants, students and nurses with regard to the descriptive definition of death with dignity in the case of a terminal patient. On the other hand, based on studied literature and on statistical analysis of the participants’ answers, we present a multidimensional and dynamic model of death quality centered on the dignity of the terminal patient.

Key concepts: *ars moriendi, good death, sufficiently good death, death with dignity, easy death, bad death, palliative care philosophy, ethics, consistency, objective list theory, hedonist theory, wish fulfilling theory, multidimensional and dynamic model of death quality centered on the dignity of the terminal patient.*

ABSTRAKT. Der würdige Tod ist ein umstrittenes Konzept und wird häufig im hbenutzt. Die Spezialisten aus diesem Bereich meinen, dass das ein künstliches Konzept sei, ja sogar sinnlos und gefährlich, zugleich stellt es eines der wertvollsten psychologischen Ergebnisse aus der Sicht des guten Notbehelfens dar. Es gibt Forschungen die zeigen, dass die Patienten, die Verluste aus der Sphäre der persönlichen

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Würde haben, als Grund, die zu folgende Aspekte führen: Mangel an Hoffnung, Depression, der Wunsch und die Bitte nach ärztlichem Eingreifen für die Abkürzung des Lebens. Es sind wenige Erforschungen betreffend der Systematisierung des Todes mit Würde, aber es gibt sehr viele Erforschungen über die Systematisierung des schönen Todes. In diesem Artikel werden neben einer sehr kurzen theoretischen Präsentation des Themas zwei Gruppen von Personen analysiert: Studenten der Fakultät für Psychologie und Spezielle Psychopädagogik, beziehungsweise Krankenschwestern. Es wird einerseits die beschreibende Definition des Todes mit Würde bei einem Patient in letzter Fase der Krankheit präsentiert und andererseits wird es anhand der Fachliteratur und der statistischen Bearbeitung der Antworten der Teilnehmer an der Erforschung ein multidimensionales und dynamisches Model der Todesqualität präsentiert. Dabei wird auf die Würde der Person konzentriert, die in der letzten Fase der Krankheit lebt.

Stichworte: *ein schöner Tod, ein genug schöner Tod, ein würdevoller Tod, ein leichter Tod, ein schlechter Tod, die Philosophie des Notbehelfens, Ethik, die Folgerichtigkeit, die Theorie der sachlichen Liste, die hedonistische Theorie, die Theorie einer Wunscherfüllung, das multidimensionale und dynamische Modell der Todesqualität zentriert auf die Würde der Person in der letzten Phase der Krankheit.*

I. Introduction

From a qualitative point of view, several differences between the processes of death exist, thus allowing us to address the concepts of: good death, bad death, easy death, death with dignity.

Due to space constraints, the presentation and comparison of the above-mentioned models are not the purposes of the present article. Additional information can be found in the materials of the authors listed in the bibliography section, as well as in the paper entitled *„Quality of death in terminal state. Dying with dignity" (Školka, 2010).*

Good death may sound as an oxymoron, especially for the modern Western society person, although humans have long been concerned with differentiating between good death and bad death (McNamara, 2001).

Currently there is an extensive literature on what is called good death. Authors like: Weisman (Chochinov, 2000); Weismen and Hackett (1961, Lester, 1996, Sandman, 2005), Kübler-Ross (1969); Ramsay (1975, McNamara, 2001); Nimocks et al. (1987, McNamara, 2001), Field (1989, McNamara, 2001); Kellehear (1990, McNamara, 2001); Kellehear (2007), Lester (1996), Kearl (1996, McNamara, 2001); Soifer (1996); Sankar (1999), Taylor (2000), McNamara (2001); Street and Kissane (2001), Pool (2003); Chochinov (2004); Goldsteean et al. (2006), McNamara and Rosenwax (2007), Wein (2007), etc. are among many other researchers who have been concerned with defining the concept.

The content of these models varies depending on the nature of the research participant samples (patients, health professionals, etc.), as well as on the greater or lesser extent to which other persons besides the patient, impacted by the quality of death (family members and friends, professionals, other patients who need medical resources, etc.) are also taken under consideration.

The model published in January 2000 by the British Medical Journal (Pool, 2003) is presented as illustration. It describes the following criteria for the good death: 1. nearing death awareness and understanding of what might happen, 2. possibility of maintaining control over unfolding events; 3. preservation of dignity and respect for privacy, 4. pain and symptoms control; 5. possibility to choose the place of death occurrence 6. access to information and professional assistance of any kind, 7. access to needed spiritual or emotional support 8. access to hospice care anywhere, not only in the hospital, 9. control on who can be present at the time of death, 10. the patient's ability to feature advanced directives in order to enforce his wishes (regarding the circumstances in which the life sustaining treatments will stop) 11. having time to say goodbye to loved ones 12. control regarding the time of these meetings, 13. occurrence of death when time comes, lack of prolongation of meaningless life.

Blasszauer (1984) showed that good death and euthanasia are often used as interchangeable concepts, although there is not a full overlap between them. Good death can occur without euthanasia, while euthanasia, in the strict, modern sense of the word, can not be imagined in the absence of adequate, good death. At the same time, empirical research shows that death by either euthanasia or assisted suicide is not always free from suffering (Groennewoud et al., 2000).

According to hospice philosophy, a normative, dominant script of the good death involves: 1. nearing death awareness, 2. open communication about death, 3. acceptance of death (McNamara, 2001), respectively: 1. nearing death awareness, 2. autonomy, independently chosen coping style; 3. open, honest communication about one's own death (Goldsteen et al. 2006). However, studies by Chochinov et al. (2000) show that patients differ in their ability to accept their adverse prognostic.

Sandman (2005) identifies the following global features of a good death: 1. the consistency between the way the person lived and the way the person dies (the congruence between way of dying and the person's actual or ideal self - values, norms in which the person believes -. The problem with this criterion only consists in the fact that the set of values and goals people follow need not have an internal consistency, the same author shows), 2. the meaningful death [Sandman emphasizes that not all the patients share the idea that their deaths would make sense - a good purpose - some will not find any meaning for their death and therefore should not be forced to find one. If one believes in such a sense, this should be respected even though experts disagree. In line with many other authors, Sandman believes that the facilitation of investing life with meaning until the last moment is a process that contributes to the good death. Studies of Nakashima's and Candle (2005), Neimeyer, R.A. (2002) confirm this idea] 3. dying with dignity (discussed below).

A good enough death was described by two prominent practitioners of palliative care. Campbell (McNamara, 2001) in 1990, defined it as the death that occurs in those circumstances that are as close to what the patient would have chosen if he/ she could as possible, while Ashby and Komesaroff (McNamara, 2001) in 1995 emphasized as characteristics of the good enough death the importance in maintaining the integrity and congruence between the death and life the person lived.

McNamara (2001) shows that these models have the advantage of being closer to the patients' reality because several individuals do not use the time that remains available to talk openly about death, to prepare and accept it. However, both good and good enough death can be criticized from ethical and philosophical points of view: while good death – „may be prescriptive" (death awareness, patients' open communication about as well as acceptance of own death can be expectations that pressure the patient assisted in the hospice system), the good enough death „may be so loosely constructed that it eventually lacks shared meaning "(p. 52) and can imply very personal - individualistic – ways of dying.

Several studies have examined what is termed good death; however a small number of studies have explored **dignity in terminal state**, as Chochinov et al. (2004) show.

Canadian philosopher Simpson (2004) notes that dignity is an expansive concept which is present in: treaties, codes of ethics, the debates on: the right to live, the right to die, the quality of life, but at the same time can be considered an empty, dangerous, unstable, self-saboteur concept. Street and Kissane (2001) argue that dignity is a central concept in palliative care lectures, the authors often relying on the tacit assumption that its content is unproblematic, its meaning is clear to everyone, although this is obviously not the case.

Saunders and Bain (1983, Sandman, 2005) have argued that this concept can create so much confusion that it would be worthwhile to avoid its use in the context of palliative care. Macklin (2003, Chochinov, 2003) also considered it useless, worthy of being removed from the scientific literature since by all means that would not cause any loss.

Even since 2001, Chochinov, et al. found that the term of dignity, used both in clinical and philosophical fields, has an ambiguous connotation. The loss of dignity may be one of the common means which lead some patients to the loss of desire to live and to the request of euthanasia and assisted suicide (1996, Back et al, 1996, Emanuel et al, 1998, Meier et al, 1991, Van der Maas et al. etc. by Chochinov et al. 2001). Chochinov et al. (1995, 1998, 2000), Chochinov (1998, 1999, 2000, 2001), Ganzini et al. in 1999 and 2000 (by Chochinov et al., 1998, Chochinov, 2001, Chochinov et al., 2001), Tataryn and Chochinov (2002) and many other authors have shown that (major) depression and especially hopelessness increase the wish for the occurrence of death. Studies by Chochinov (2002) and Chochinov et al. (2002c) show that the loss of dignity can intensify negative feelings and thus may increase the wish to die.

Toombs (2004) shows that in everyday life dignity equals personal worth. Being treated with dignity means being considered valuable, being treated with respect. Losses within dignity imply the reduction of that person's value. Chochinov et al. (2004) define dignity as the quality or state "of being valued, honored and respected" (p. 134).

Chochinov (2002a) shows that the scientific literature refers to a *basic dignity* - specific to any human being, on one hand and to a *personal dignity* - "a more individualistic, transient and tied to personal goals and social circumstances" construct, on the other hand (p. 2256).

Bandura (2001), Barrett and Behne (2005) describe agency as the characteristic specific to an entity capable of goal directed actions.

This position is problematic in that it leaves out the human beings that no longer are persons respectively overlooks the dignified treatment of the human body after death.

As philosopher Soifer (1996), citing Cranford, infers, even if certain human beings lost their ability to be persons, namely those who no longer are moral agents – are biologically alive, without being conscious, without ever again having the ability to feel pain or pleasure, this does not warrant others to behave in a disrespectful manner with them.

For example, the manner in which the patients confronting with persistent vegetative state (PVS)/ post-coma unresponsiveness (PCU) are treated rather influences others than the patients as individuals. Soifer also argues that if the path towards abuses is taken, the risk of the acquisition of a disrespectful attitude towards human life in circumstances when this respect is necessary would be present; this in turn could have an indirect negative effect on the obligations towards the individuals who are not in a PVS, but could fall in such a state. For this reason, those persons that do not want their bodies to be treated in certain ways (medical experiments, organ prelevation etc.) need to be assured that this type of unwanted treatment would not happen in their case; the family members, the friends of patients in a PVS may wish that their dear one is not kept alive by any possible means, may desire to deny the organ prelevation or the research etc.

The fact that a deceased person's previous wish is respected or not impacts the well being of the living ones. The respect for the deceased person's wish is a way to respect his autonomy. It seems that certain commitments/ duties towards individuals in a PVS truly exist, not because they are persons, but because they once were. Thus, they exert an influence on other humans, even after they ceased to exist as persons (Soifer, 1996).

Therefore, the capacity for autonomy is the only criterion that can explain the reason why several commitments/ duties towards individuals in a pervasive vegetative state exist "(…) the source of these commitments is the obligation to respect the autonomy of others" (Soifer, 1996, p. 47).

Based on a study representative for the elderly population suffering from cancer, Chochinov et al. (2001a, p.4; 2004, p. 138) framed the so-called *personal dignity model*, within which they identified three major dignity categories, each of them having, in the authors' perspective, a number of themes and subthemes. These are: **1. illness related concerns** (*1.1. level of independence:* cognitive acuity and functional capacity in carrying out daily activities; *1.2. symptom distress*: physical distress; psychological distress (medical uncertainty, death anxiety). **2. dignity conserving repertoire** *(2.1. dignity conserving perspectives:* continuity of self, roles preservation, generativity/legacy, maintenance of pride, hopefulness, autonomy/control, self acceptance, resilience/fighting spirit *2.2. dignity conserving practices*: living in the moment, maintaining normalcy, seeking spiritual comfort **3. social dignity inventory**: privacy boundaries, social support, care tenor, perceived burden to others, the concerns about the impact of own death on others/aftermath concerns. The *personal dignity preservation model* provides information regarding the interventions which can help to maintain a sense of personal dignity.

Chochinov (2002a) argues that each person would attach various degrees of emphasis on these categories of the dignity model. As a result, the concept of dignity will differ from one person to another, from one circumstance to another. At the same time, the feeling of personal dignity may fluctuate, depending on a series of factors (Chochinov, 2002a).

Street and Kissane (2001) highlight some important aspects of dignity, namely: 1. its socially constructed nature (several different culturally saturated scripts of dying with dignity exist, depending on the interests of the particular groups) 2. its relational build nature (mutual, build on and maintained by feed-back, lived within the intersubjective space) 3. its embodied nature (the manner in which those concerned – both patients and caregivers – experience the patient's body degradation, 4. its deeply subjective (personally perceived and lived) nature.

According to Sandman (2005), as dignity is a notoriously unclear concept, the establishment of its subcomponents within the daily work of palliative care would be appropriate. The author also reflects on the possible relevance of these subcomponents for the issue of good death.

In Sandman's view (2005) *a certain way of the dying person to relate to himself (self-esteem)* has the greatest potential to ensure a good death. In the same train of thought, Frank (1995; Radley, 2004) discusses the importance of the fact that the patient stays in love with himself. A much lower potential to produce a good death relies in the *person's status*; a far more rare component of patient's dignity is the ability to inspire and arouse awe in others. This type of dignity can be effective in terms of good death mainly through the gratification and care that the patient can receive from people who admire him. A *certain personality or character trait, that defines an aristocratic type of dignity* - incorporating excellence, distinction, distance, self-control - may more frequently contribute to a less good death because of the self-control effort and the loneliness it implies, except for those individuals for whom dying with such dignity represented a life value and therefore it also constitutes an important value during the dying process. The main reasons for which this type of dignity could contribute to a better death lie in the fact that it can be instrumental for the obtaining what the person wants or likes or the fact that it contributes to a decreased tension within relationships. Wein (2007) identifies the courage – which is, as Aristotle shows, under voluntary control – as „a critical ingredient in coping with the terror of dying" (p. 42).

From an anthropological perspective, Bloch and Parry (Poole, 2003) consider that the **bad, inadequate death**, is characterized by the absence of control. The bad death is generally a death full of pain, trauma, prolongated suffering, loneliness, lack of meaning (Taylor, 2000).

Kellehear (2007) perceives shameful dying as dying without dignity, associated with: „material hardship but also the dependency wrought by frailty, contagion and the prospect of a disappearing identity" (p. 215). In McNamara's (2001) view, bad death traumatizes the patient, the family members and friends, challenges the palliative care purpose, complicates the organizational maintenance, drains the care giving professionals resources (p. 47).

Several authors argue that ultimately the individual in question is the only one that can determine the extent to which his death is or is not good. As Weismann (Poole, 2003) shows, "the good death is the death that someone would choose if they had a choice" (p. 8).

According to Sandman's (2005) opinion – the only "truly acceptable" guideline based on which one can ethically answer the question about what needs to be done within palliative care in order to add value to the dying persons' life - is the analysis of the consequences of acts and attitudes (consequentialism). The same author states that all the individuals involved must be taken into account - all the patients, all the family members and friends, all the professionals, even those who are outside the healthcare system.

In order to be able to decide which of the acts and attitudes leads to the best results an idea about what is good in life is needed – namely, a theory of value, of what is good in life (Sandman, 2005). Three theories circumscribing what is good for the individual are disseminated within the philosophical literature: hedonistic theory, desires fulfillment theory and object list theory (1984, Parfit; 1996, Griffin, 1998, Brülde cited by Sandman, 2005, p. 7). *Hedonism* – namely the experiential well-being (seeking pleasure and avoiding pain) – constitutes the essence of good life, although reasons that determine the individual to abandon the well-being in order to fulfill certain desires, or appeal to the objective list may arise in life; *desire fulfillment theory* is based on the idea that if a person really wants something and his/ her wish is fulfilled, this will make the individual feel better, irrespective of the positive or negative effect of this achievement on his/her well-being (Sandman, 2005); *object list theory* - includes matters that are good for the person, regardless of the fact that the person wants them or not, or that they have a positive or negative effect on his/her well-being. Brülde (Sandman, 2005) showed that these factors contradict (they cannot be simultaneously and completely satisfied, they can be in competition or conflict). According to Sandman (2005), this list includes those phenomena that may be related to good death: *1. achievements, 2. intimate personal relationships, 3. contact with reality; 4. to be a certain kind of person; 5. self-determination 6. freedom.*

McNamara (2001) argues that there are many ways of dying, each associated with a multitude of personally and culturally shaped meanings and all represent certain social constructions. The construction of the idea of good death - is a theory, a model which should always be contextualized in order to be <"more inclusive, integrated and useful"> (McNamara, quoting the words of Kastenbaum and Thuell, 1995, p. 42).

Goldsteen et al. (2006) warns against the danger that the actual normative script of good death from palliative care field "might function as a reductionist and restrictive force in actual care for the dying patients") so that they ultimately feel compelled to live up to expectations created by these standards (p. 384). In fact, people have their own standards and values and" each die their own unique death" (idem).

II. Methods, samples and results

Methods

The present paper concerns the results obtained from the processing of answers given to the question *„In your opinion, what is the meaning of dying with dignity in the case of a terminally ill person?",* by two participant samples, results derived from an ample research, that targeted: (1) the examination of the psychometric properties of the assessment scales used, 2) the analysis of the frequency distribution and the significance of differences among answers given to a questionnaire containing 37 questions that focused on representations, beliefs, knowledge about and attitudes towards the terminally ill patient and death, medical intervention nonintervention concerning end of life in terminal state (MINELT), (3) the analysis of mean difference significance for several variables, (4) the analysis of Pearson correlations between the selected constructs, (5) simple regression analysis, and (6) path analysis, respectively.

Both quantitative and qualitative methods were use for data processing. Given the open-ended type of questions, the rough responses were gradually grouped by means of the qualitative analysis (Gay, Mills and Airasian, 2006) into simple analytical categories and afterwards quantitatively analyzed. Subsequently, they were regrouped into superordinated categories, based on other criteria for classification. The data processing was performed using SPPS application for Windows, version 15.0, aiming the distribution of answer frequencies, both within and between groups as well as the statistical significance of differences using the Chi-square test. By the end, following a qualitative analysis, the analytical categories were subsumed to the multidimensional and dynamic model of quality of death, centered on dying with dignity, proposed by the author, based on information from scientific literature and the present statistical processing.

Samples of subjects

Individuals clustered in five groups participated in the ample research. Their selection was based on simple randomization. The current article presents the analysis of the responses originated from two groups: nurses (N) and students from Special Education and Psychology departments (SSE-P). The collection of data from these two groups was accomplished in 2007.

Nurses from medium sized urban hospitals [N = 43, gender: F = 32 (74.4%), B = 11 (25.6%), nationality: Romanian - 41 (95.3%); Hungarian - 2 (4.7%), minimum age - 22 years, maximum age - 54, average age - 33.76. Self-reported intensity of religious belief: N = 11 (26.8%) high, N = 28 (65.1%) moderate, N = 2 (4.9%) poor, N = 2 no answer].

Students from three university centers [N = 185, gender: F = 161 (87.5%), B = 23 (12.5%), N = 1 no answer. Minimum age - 19 years, maximum age - 53, average age - 23.07; Special Education department: 99 (53.5%) students; Psychology department: 86 (46.5%) students; Years of study: II = 30 (16.2%) students; III = 105 (56.8%), IV = 50 (27%) self-reported intensity of religious belief, N = 55 (29.9%) high, N = 119 (64.7%) moderate, N = 10 (5.4%) poor, N = 1 no answer].

Results and conclusions

1. The frequency of number of elements regarding dying with dignity, generated by the two samples

The number of answers (semantic units) generated by the members of the samples ranged between one and five.

Within group analysis

A number of N = 179 students (96.8%) of a total of N = 185 provided semantically valid answers. N = 2 persons provided semantically incorrect answers. N = 4 individuals did not answer this question.

A number of N = 37 nurses (86%) of a total N = 43 provided semantically valid answers. One person answered "I do not know." N = 5 people did not answer this question.

Between groups analysis

The following numbers of descriptive definitions of dying with dignity were generated: *one element* (by**:** 50.8% of SSE-P and 45.9% of N); *two elements* (by**:** 37.8% of N and 31.8% of SSE-P); *three elements* (by**:** 14.5% of SSE-P and 8.1% of N); *four elements* (by: 2.7% of N and 2.2% of SSE-P); *five elements* (by: 5.4% of N and 0.6% of SSE-P).

Chi square test table (Školka, 2009) indicates that in the case of the variable concerning the number of items that describe the dying with dignity, there are **no significant differences** between the two samples ($\chi 2 = 6.63$, $p > .05$). The observed differences are due to chance.

Conclusion: *Most of the nurses and almost half of the SE-P students provided a descriptive definition of the dying with dignity concept using one element, followed by those that used then two elements. The differences are not statistically significant, the null hypothesis cannot be rejected.*

2. The frequency distribution of the answers regarding the descriptive definition of dying with dignity of the terminally ill persons, obtained after analytical coding of the answers

2.1. Within group answers analysis for SSE-P

A number of 303 valid answers were generated by a number of N=179 students (96.8%).

2.1.1. Analysis of answers that occurred with the highest frequencies

In a decreasing order of frequencies, SSE-P enumerated the following elements of what dying with dignity means:

- 13.5%, corresponding to the highest percentage of the sample answers – the acceptance of death; followed by 8.6% - accepting the situation, respectively a similar category - accepting the naturalness of death (2.6%). In sum, these three categories of answers represent **24.7%** of the total number of answers generated by the students of the two departments. Ordinarily, these categories can be considered as very close from semantic point of view (death acceptance - accepting the naturalness of death, death acceptance - accepting the situation given that the "situation" the patient is facing consists of the terminal condition - explicitly stated in the question content). However - as indicated by students' answers to other questions of the questionnaire, some of them considered that there is hope for healing in the terminal stage, that medical miracles can occur, or that the whole truth about the diagnosis should not be communicated to the patient. Thus, for some of the respondents „acceptance of the situation" meant "acceptance of the disease"- a form of dismissal of the idea of nearing death in favor of approaching the idea of "being just sick".
- percentage of **8.3%** of the responses conceptualize dying with dignity as implying (in one way or another) the patient's care towards his family members and friends: not to be a burden for family members and friends (3.3%), absence of blame towards professionals and/or family members (1.7%); protection of family members and friends (1.7%), avoidance to inflict suffering on family members and friends (0.7%), encouraging the survivor family members and friends (0.3%); creation of happy moments for family members and friends (0.3 %); preparing the family members and friends for the patient's death (0.3%).

▪ the faith in God, in the hereafter has been identified as an element of dying with dignity in **7.3%** of the responses, followed by: ▪ self-reconciliation **(5.9%);** ▪ repression of patient's negative emotions **(4.6%);** ▪ reconciliation with others **(4%).**

All these categories constitute **54.8%** of all the total number of responses.

***Conclusion**: The acceptance of death, of the situation, of the naturalness of death constitutes the most frequently attached element to the idea of dying with dignity, being raised in nearly a quarter of the answers generated by SSE-P sample, followed by: patient's care towards family members and friends, faith in God, in the hereafter, self-reconciliation with himself, repression of patient's negative emotions, reconciliation with others. All these represent more than half of the total of responses.*

2.1.2. Analysis of relevant responses that occurred with the lowest frequencies

Among The elements that were mentioned with a low or very low frequency among all responses generated per sample (one response corresponds to 0.3 of the total of responses), but which, according to the scientific literature, play a significant role in facilitating the patient's dying with dignity, are: ▪ the patient's ability to accept help (0.3%); ▪ the feeling of personal worth (0.3%); ▪ the preservation of self-esteem (0.3%); ▪ the respect showed by significant persons (0.3%); ▪ the self-determination (0.3%); ▪ the expression of wishes (0.3%), ▪ the expression of the patient's death anxiety (0.3%); ▪ the appropriate medical treatment of the patient (0.7%), respectively symptoms alleviation (0.3%) – those factors summing 1%; ▪ having the family members and friends nearby (1.7%).

A percentage of 0.7% of the responses state that there is no dying with dignity, 0.3% of the responses express the doubt that dying with dignity exists, and 0.3% state the idea that a dying person does not need to be dignified.

Following the table constructed on the basis of analytical coding of the responses (Školka, 2009), the contradictory elements that appeared in the descriptive definition of this fully subjective (anchored in the person's cultural value system) concept can be noticed: ignorance of the reality vs. nearing death awareness / death acceptance / acceptance of the situation; the ability to commit suicide vs. absence of suicide; expressing the death anxiety vs. absence of death anxiety/ repression of negative emotions, absence of end of life request vs. choice of the moment of death, death acceptance vs. death defiance.

2.2. Within group answers analysis for nurses

A number of 69 elements that descriptively define dying with dignity were generated by a number of N=37 nurses (86%).

2.2.1. Analysis of responses that occurred with the highest frequencies

In decreasing order of frequency, the nurses listed the following elements of what dying with dignity means:

▪ 10.1% - which corresponds to the relatively highest percentage of answers in the sample - the acceptance of death, followed by the acceptance of the situation (5.8%), or the acceptance of the disease (1.4%), all these categories summing **17.3%**

▪ 5.8% - having the family members and friends nearby, having the family members and friends, as well as the professionals alongside (1.4%), comfort (1.4%), attention (1.4%), affection family members and friends (2.9 %), having somebody nearby (1.4%), summing **14.3%;** ▪ self-reconciliation **(7.2%);** ▪ care **(5.8%);** ▪ 1.4% pain relief, 2.9% suffering alleviation, 1.4% medical care, totaling **5.7%;** ▪ reconciliation with others **(4.3%);** ▪ stoicism in front of suffering **(4.3%);** ▪ absence of pain **(4.3%).**

All these answers represent a percentage of 63.2% of the total group answers**.**

***Conclusion**: the acceptance of death, of the situation and of the naturalness of death constitutes the element most frequently attached to the idea of dying with dignity invoked in most of the answers mentioned by the nurses group, followed by: having the family members and friends nearby, self reconciliation, care and pain relief.*

2.2.2. Analysis of relevant responses that occurred with the lowest frequencies

Among the elements that were mentioned with a low or very low frequency among all responses generated per sample (one response corresponds to 1.4 of the total of responses), but which, according to the scientific literature, play a significant role in facilitating the patient's dying with dignity, are: ▪ respect for the patient (1.4%), lack of humiliation (1.4%) - representing 2.4%; ▪ patient's self-actualization (1.4%); ▪ absence of unnecessary prolongation of suffering, against the patient's will (1.4%).

A percentage of 2.9% of total number of responses refer to doubts over the existence of dying with dignity. Several responses showed hat the nurses' evaluation of the patient's dying with dignity was accomplished based on the relationship between health professionals and family members and friends [communication with family members and friends (1.4%); satisfied family members and friends (1.4%)].

The analysis of the analytical categories in case of nurses reveals that the descriptive definition of this concept is fully subjective (anchored in the person's cultural value system). The nurses - very few in number - have used some contradictory (fight till the end vs. the wish for euthanasia) and inadequate elements: the absence of death anxiety, the wish for euthanasia.

3. Frequency distribution of the answers regarding the descriptive definition of dying with dignity of terminally ill persons, resulting from the re-codification of analytical categories in superordinate categories

The analytical categories were subjected to a new categorization, based on the criterion of the (implicit) contributor to the occurrence of dying with dignity (namely, the locus of control of this phenomenon).

Thus, the following five superordinate categories of answers were obtained, depending on the factors involved in causing the dying with dignity:

1 - dying with dignity predominantly involves the patient (internal locus of control) This category subsumes answers like: absence of unaccountable demands from the patient, patient's protection of family members and friends, absence of revenge, religious belief, meaningfulness of the patient's life, absence of the patient's envy, nearing death awareness, the patient's repression of emotions; self reconciliation, reconciliation with own life, resistance to pain, lack of remorse, generativity.

2 - dying with dignity predominantly involves the family members and friends (external locus of control)

This category subsumes answers like: not to be mourned during lifetime, not to be a burden; closeness of family members and friends, absence of the significant others' pity for the patient.

3 - dying with dignity involves the patient and the family members and friends and / or the professionals (interpersonal locus of control/ shared control)

This category subsumes answers like: awareness that everything possible was done in order for his/ her healing, avoidance of infliction of any suffering for family members and friends, preparation of family members and friends for the patient's death, absence of blame towards professionals, reconciliation with others, the belief that family members and friends will be well after the patient's death, lack of obligation to bribe, expression of wishes.

4 - dying with dignity involves the life context, several different factors (external locus of control)

This category subsumes responses such as: choice of the place of death, easy death, adequate treatment, preservation of self-esteem, sense of personal worth, quick death, functional autonomy, absence of prolonged suffering.

5 - dying with dignity outside the previously described categories

This step implied the computation of the frequency of occurrence of the superordinate categories within each answer given by the sample members, thus obtaining: simple superordinate categories (from answers which include a single semantic unit) and combined categories (from answers which include more semantic units) - in order to determine the frequency with which people in the two samples have produced different answers.

3.1. Within group analysis

3.1.1. Students from SE-P departments

Following quantitative analysis of answers (Školka, 2009), it appears that 60.3% of the students generated responses which implicitly transmitted the idea that the patient's dying with dignity depends on himself. The following were, in decreasing order of percentages: those who answered that the patient's dying with dignity involves the context (14.5%); the patient, the family members and friends and the professionals (5.6%) the patient and the context (5.6%); the family members and friends and the patient (4.5%), the family members and friends only (3.9%). A percentage of 1.7% of the total number of students adopted the view that the dying with dignity involves the patient, family members and friends, professionals, alongside the life context.

3.1.2. The nurses

Following quantitative analysis of answers (Školka, 2009), it appears that 43.2% of the nurses have generated answers which implicitly transmitted the idea that the patient's dying with dignity depends on himself. The following were, in decreasing order of percentages: those who answered that the patient's dying with dignity involves the context (10.8%); the patient, the family members and friends and the professionals (8.1%), the family members and friends and the context (8.1%); family members and friends only (5.4%); the family members and friends and the patient (5.4%). A percentage of 5.4% of the nurses explicitly stated either that dying with dignity does not exist or it should not exist. A percentage of 1.7% of the total number of nurses adopted the view that the dying with dignity involves the patient, the family members and friends, the professionals, alongside the life context.

3.2. Between groups analysis

The answers formulated implicitly transmit the idea that the following are involved by default in dying with dignity: the patient (60.3% of SSE-P, 43.2% of nurses); the context (14.5% of SSE-P, 10.8% of nurses); the patient, the family members and friends and the professionals (8.1% of nurses, 5.6% of the SSE-P); the patient and the context (5.6% of the SSE-P, 2.7% of nurses); the family members and friends and the patients (5.4% of nurses, 4.5% of the SSE-P); the family members and friends (5.4% of nurses, 3.9% of the SSE-P); the patient, the family members and friends, the professionals and the context (nurses 2.7%, 1.7% SSE-P).

Chi square test table indicates that in the case of this variable, regarding the instances implicitly involved in the terminally ill patient's dying with dignity, there are **no significant differences** between the two samples ($\chi2 = 18.87$, $p > .05$). The existent differences are due to chance.

Conclusion: *most of the SSE-P and almost half of the nurses identified elements* ***involving*** *the patient's participation to his/ her dying with dignity, followed by those who generated elements implying that the dying with dignity predominantly depends on the context, respectively by those who think that it depends on the patient, the family members and friends and the professionals. Differences are not statistically significant, the null hypothesis could not be rejected.*

III. A dignity centered multidimensional and dynamic model of quality of death in terminal state

Based on theoretical assumptions from the scientific literature, conveyed by different authors within the field of psycho-social sciences (cited in the first part of the material) and on the analysis of the research participants' responses, a multidimensional and dynamic model of the quality of death, centered on the patient's dignity was conceptualized, in a manner that facilitates the understanding of this phenomenon in the didactic process.

In an atomized form (which obviously does not totally overlap with the complexity of reality), the major dimensions affecting the patient's dying with dignity are:

1. the dignity derivable from the general/basic human level
2. the dignity derivable from the patient's individual level
3. the dignity derivable from the interpersonal level
4. the dignity derivable from the context in which the dying person lives.

The result of the interaction between these dimensions constitutes the quality of dying. The model distinguishes between the good death, the dignified death (as a possible subcomponent of good death), easy death (as a possible subcomponent of the good death, but not also of the dying with dignity) and bad death.

The underlying ideas of this model are:

1. *There are qualitative differences between different death processes,* as certain ways of dying are more favorable for the individual (and/or family members and friends) than others. The quality of the dying process is understood here as: the quality of life during terminal state, the quality of the dying act itself, as well as the quality of others' approach to the deceased human being, during the period when the physical separation between the living and the dead has not yet been finalized.

As Weisman described the dying is viewed as good if it coincides with the manner in which the person *would want* to die (for example, to die in his sleep, to be lucid until the very last moment of life, to be free from pain etc.), in the hypothetic situation that he/ she is well-informed and would have the choice. It can also be a good death if the family members and friends, along with competent, honest and right-minded professionals make jointly decisions in the major interest of the patient when he is no longer able to do so. The good death constitutes a superordinated category of dying with dignity and/or easy death categories. Someone can die a dignified death, without the other elements that make up the good death (founded on the objective list, hedonist and/or wish fulfillment theories– as Sandman conceptualized) to be present. One such situation is the patient who, even if suffering intensely, decides not to express his pain in order to preserve his dignity. In other words, despite adequate treatment, the patient passes through an intense suffering, the process lasts much longer than he wished or hoped, and while showing stoicism during the dying process in order to preserve dignity, the intrapsychic suffering deepens (by experiencing loneliness, unfulfillment, by the experience of not being basically understood by others, by being rather respected than loved, by being confronted with an intense existential pain, ontological guilt with the belief that he had wasted his life, that his life had no meaning etc.).

Dying with dignity implies that:

a. the former person is treated with respect regardless of the current value (the minimal criterion of general/basic human dignity, as defined by Chochinov, Soifer), and if the former person's values, style, preferences are well known, he/she will be treated accordingly – under reasonable limits, obviously – throughout the dying process and after death, thereby honoring the individual who once was (the maximal criterion of personal dignity)

b. the person holds the quantity and quality of self-control/shared control, self-determination, either *desired* or *self-imposed*, as well as an adequate self-esteem and freedom (the ability to make choices between personally valuable alternatives).

Easy Death - the actual act of dying – represents the naturally produced death, that occurs quickly and without suffering, though for these reasons precisely has nothing to do with dignity (it lacks the confrontation with the death as a process with all its consequences, neither the patient nor the family members and friends or the professionals have the possibility to make choices regarding its pace/ time and quality).

Bad death is the traumatic, dehumanizing, needlessly long as a process/ occurring earlier than needed and wanted, meaningless, etc. death.

2. *the quality of death is deeply social, personal and contextually constructed.* Several objective and objectivizable components interfere with the quality of death (a). Beyond these, major - culturally dependent – scripts/narratives regarding the meaning of the four types of dying mentioned above are shared between people (b). On the other hand, a personal significance (c) is added to these two components, which may be more or less consistent or inconsistent with the major narratives. The personal meanings constructed regarding to the four types of dying are profoundly subjective and depending on the patient can be grounded in completely opposed values and beliefs (relieving suffering at all costs vs. enduring suffering to preserve lucidity, euthanasia vs. enduring suffering for its intrinsic value, restricting the access of significant persons vs. the desire to have all the loved ones close by at the moment of death, etc.).

Important / significant differences can exist within the quality of death attributions, depending on who makes them (the patient, the family members and friends, the professionals). The present model focuses on the patient's perspective in a sistemic manner.

3. the dying *person, the family members and friends, the medical professionals and the context* in which the terminal state unwinds *are both potential generators and dispossessors of the dying with dignity* (in descending order of the listed dimensions).

The individual itself is - potentially - the most prolific generator of dignity within the process of his own death (as the personality, the values, the relationship with himself, along with the coping strategies strongly affect the manner he faces this challenge). At the same time, however, the individual can diminish or harm his own dignity by behaving in certain ways (for example, by choosing to repeatedly offend, insult the professionals, the family members and friends); even if the person is dying, as long as he/she possess agency, also possess moral responsibility towards others.

The family members, friends and the professionals have many available means to either compensate or damage the patient's dignity. This is accomplished on the one hand, by either relating or not to the patient as a whole (caring for the person and not just or mainly his/her organs or body), by relating to the patient with the respect that he personally deserves and is inherently human and on the other hand by being close to him in a way that increases the person's self-determination (for example, ensuring decisional control for the patient who has a reduced functional autonomy, but is mentally competent) and freedom (creating more valuable possibilities to choose). The lower the person's ability to secure and protect his own dignity, the more the protection of dignity depends on the other persons, under extreme conditions depending on them entirely.

The context in which the person lives, by either ensuring or not the resources and instruments needed and proper laws, represents another generator or dispossessor of dignity and dying with dignity. The ecological factors are highly mediated by the relational dimension.

Compensation processes may occur in some limits between the various factors which generate dignity when the "capacity" of some of them to produce dignity is reduced, greatly reduced or even missing, if efforts to generate dignity are made by the capable factors. For example, the physically functional, but non-discerning person can be prevented from doing reprehensible acts that he/she would certainly not have done during the lucid life, by supervision and gentle control – his/her dignity being thus protected.

Rather didactically, the multidimensional and dynamic character of the quality of dying, centered on the dying with dignity may be symbolically illustrated in a form of an irregular tetrahedron, with the following sides, namely subcomponents (assuming that the list is not exhaustive; the subcomponents regarding rather the good death than the dignified death are marked by *):

P - is the side of the tetrahedron with the largest area, as it symbolizes the purely personal dimension of human dignity, which, as long as the individual has agency, can "produce" the most significant "quantity" of dignity during the dying process, via his choices/decisions.

The following are subsumed to this dimension:

1. **The bodily/structural dimension** (concerns the sick body - its integrity-disintegration -as social stimulus: the attractive, neutral, disagreeable character, in the manner this dimension is approached by Street and Kissane, ect.)
2. **The functional and intrapsychic features dimension**

a. *The physical and mental competence* [degree of functional physical autonomy, degree of mental autonomy (contact with reality, discernment kept (the competent patient) ← dysfunctions, psycho-organic disorders of subclinical and clinical intensity → loss of the agency/ quality of being a person/ incompetent patient) - similar with Chochinov et al.'s conceptualization, etc.]

b. *The mental suffering in response to physical and psychological symptoms* (dysfunctions, reactive mental disorders to terminal condition) - similar with Chochinov et al.'s conceptualization

c. *The relationship with self* (self acceptance/ self-reconciliation, self-love, self-worth/ self esteem, continuity of personal identity * - their opposite) – idea discussed by a number of researchers, among which Sandman also

d. *The personality, attachment style and personal expression style - being a certain kind of virtuous person* – (self-control, courage, stoicism, frustration tolerance, discretion, sensitivity, fairness, compassion, empathy, altruism, humor, respect, etc. - their opposite) – idea also formulated by Sandman

e. *The self-determination*

3. **The existential dimension**

a. the *affirmation of life and reconcilement with life* (desire to live; pleasure to have lived; regrets for the past, regrets for the future) - (meaning, purpose, achievements in life / self actualization, generativity; pleasure / joy, beauty *; hope *; activism and involvement until the end of the existence – the opposite of them)

b. *confronting with death*-[death awareness, double consciousness, avoidance of death, acceptance of death naturalness, (at cognitive and emotional level) acceptance of own death nearing/imminence, meaning of personal death*, preparation for the nearing death (ending of earthly accounts, saying goodbye, etc.)]

4. The spiritual dimension

a. *religious* (religious preparation for death, death rituals)

b. *secular (agnostic, atheist)* – (symbolic immortality, ecological immortality) *

R – is the side with an area smaller than P because it symbolizes the dimension of interpersonal relationships of the dying person. The dignity potentially derived from this dimension of the relational ethics (in the sense of the concept used by Böszörményi-Nagy Iván (Goldenberg and Goldenberg, 2006) – founder of the contextual school in systemic therapies) is considerable (in the case that the family members and friends – if available - and the professionals are involved, honest, competent, right-minded, sensitive to the patient's needs and capable of respecting the patient's self determination, increasing his freedom when possible). The patient's dignity facilitated, protected by dimension R arises based on:

- Personal merit/entitlement, accumulated by the patient throughout his life and his nearest past
- The manner in which the dying person copes with the debts towards others (family members and friends and professionals)
- The manner in which the family members and friends cope with the debts they accumulated towards the patient
- The manner in which the professionals cope with their professional obligations
- Respect for the individual's uniqueness, for his self-determination; moreover, even in the case of fluctuating, shortage of or total absence of discernment, honoring the person that one was, by the quality of care, by the facilitation of preservation of the living standards to which the patient once adhered, if known - obviously within the possible and reasonable limits. This dimension concerns the right, context-dependent balance between the acts of receiving and giving among those involved.

The following are subsumed to this dimension:

a. *the respect towards the patient's person, uniqueness* (from family members, friends and professionals)

b. *the patient's quality of being a significant person in somebody's lif*e* (existence of intimate, meaningful personal relationships – idea also formulated by Sandman)

c. *the social (instrumental, emotional, informational) support received by the patient and the basic attitude with which the caring is ensured by family members, friends and specialists* (not being a burden, satisfaction of patient's needs and desires (communication, care, medical treatment, special wishes, etc.), honoring/valorization of the patient's life*; adequate emotional and behavioral self-regulation of the family members, friends and professionals)

d. *the fair distribution of resources by the professionals* – idea also formulated by Sandman

e. *the patient's social adaptation and the social support (instrumental, emotional, informational) offered by the patient* – (the patient's respect towards the ones involved in his assistance, the patient's appropriate emotional and behavioral self-regulation, the protection of family members and friends, the preparation of the family members and friends for the patient's death and their encouragement)

f. *the patient's reconciliation with others** (conflict resolution, understanding the mistakes of others, forgiveness of others, understanding towards the patient's mistakes, the patient's forgiveness by others)

g. *the shared control (patient-family members and friends-specialists)*

h. *the possibility to bid farewell**

i. *knowing that the family members and friends will be well and safe after his death* * - idea similarly formulated by Chochinov et al. also

j. *the family members and friends' support by professionals* *

C - is the side of the tetrahedron with the smallest area, because the dignity derived from this context is lower than the one derived from the P and R areas, as the dignity that occurs within C is strongly mediated by the variables: patient and his interpersonal relations.

Dimension C refers to the dignity that can be derived from the physical, political, economical, legal context in which the patient lives and the higher the deficit in this area, the deeper negative its impact.

The following are subsumed to this dimension:

a. *economic resources* – (belonging to the patient and the family members and friends, to the system of care)

b. *informational resources*

c. *instrumental resources, medical materials*

d. *physical environmental resources* (appropriate context of dying – the opposite of this)

e. *legal resources* [health policies, legislation that regulates: a fair division of resources between patients, patient's self-determination (including medical interventions / non-interventions for deliberate shortening of patient's life, at his request in terminal stage: euthanasia, assisted suicide)].

U – is the base of the pyramid and its thickness is slightly higher than that of the other sides, as it symbolizes the generl/basic human dignity, independent of the personal/contingent dignity (as understood by Chochinov; Sandman, Soifer, etc.).

It is the type of dignity deserved by any member of the species, including those who never had or lost their agency and those that meet all the criteria for being declared dead. In this case, the beneficiary of the respectful care is not the patient himself, but rather the family members and friends and any member of the species that can reach a similar situation and for reasons derived either from the attachment towards own body or from religious beliefs, they wouldn't like their body remains to be treated in a disrespectful manner. Ultimately, it represents the respect for the patient shown in the interest and for the benefit of others, including those who show it.

Axis T – from the inside of the tetrahedron, symbolizes the duration (beginning and end) of the terminal state. This factor reflects the difference between: the early death, the death that occurs at the right moment, the late death (occurring much later than the moment considered right by the patient).

In order to illustrate the multidimensional and dynamic nature of dying with dignity and ultimately, the deeply idiosyncratic character of what this phenomenon means for each patient, let's imagine the sides of the tetrahedron colored (P - Red R - Blue, C - Yellow, U - green) or build from different little geometrical shapes, and the dignity „generated" by each side as "dignity atoms", having the same color/ texture of geometrical shapes as the side/dimension in which it was "generated".

Figure 1a. shows the four dimensions of dying with dignity, with the „dignity atoms" specific for each dimension.

The inside of the tetrahedron - its volume - is filled with the "dignity atoms" of different colors/shapes, which interact in „chemically" unique manners with each system consisting of patient, family members, friends and professionals each living in their own contexts. Out of these unique interactions, unique compositions are derived, each perceived by individual patients in a personal manner.

Dignity within the death process can be illustrated by the mixture of the different colors/ shapes of "dignity atoms", resulting in different compositions. The mixture of colors/ shapes in the symmetry center of the tetrahedron is representative for the dignity the person generally experiences during his/ her dying process. Close to the tetrahedron walls, the "mixture" of "dignity atoms" is more heterogeneous, meaning that dignity fluctuations are common to everyday life.

Figure 1b. illustrates a model of good (and) dignified death, in which the quantity and interaction between the dignity atoms produced by the four dimensions, together with the „proper" axis of time (the terminal state duration) determine this result for the patient. The arrow that starts from the point of symmetry of the tetrahedron points to an irregular shape, positioned above, illustrating "microscopically" a sample of the basic composition of dying with dignity. The second irregular shape (positioned below the first one) illustrates the subjective experience of the quality of death, experienced by the patient.

There are differences from one patient to the another in terms of the optimum "quantity" and "composition" for dying with dignity (different colors and shades/ patterns of geometrical shapes of the dying with dignity will represent the meaning of dying with dignity for different patients). Some choose a dignified behavior, which they maintain despite all the difficulties, others do not experience losses within dignity while they search for less pain and more pleasure. Specifically, some individuals will adhere more strongly to the wish fulfillment principle than to the hedonism principle and the objective list. In the case of others, the choices are dominantly made on the basis of the hedonism principle etc. These (conscious and unconscious) choices also affect the quantity of, and the interaction between the "dignity atoms" from different areas and influence both objectively and subjectively the experience of dignity in the dying process/ the quality of death.

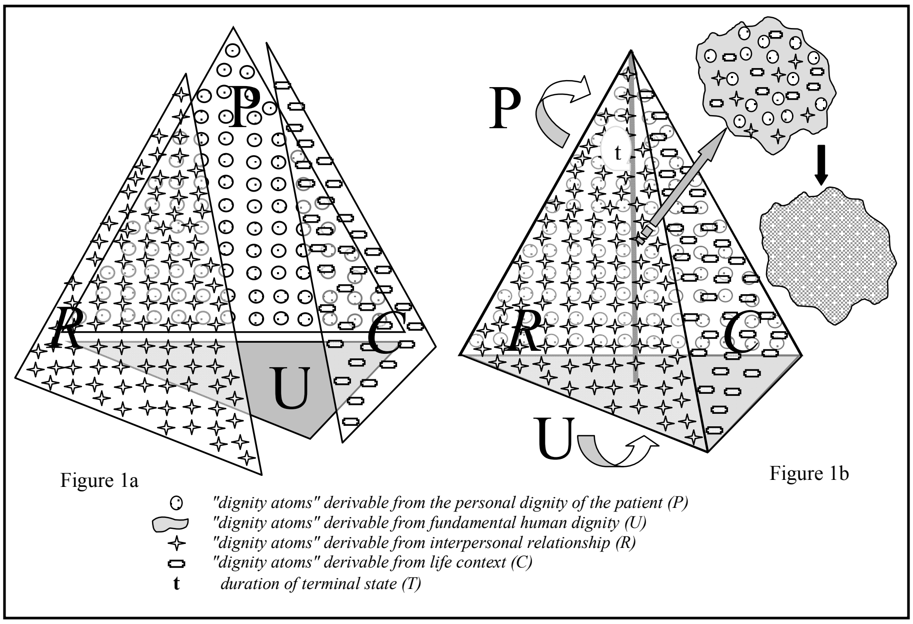

Fig. 1a and 1b: A model of good death with dignity

It is possible that the same amount of dignity - within certain limits – to be obtained through different compositions of „dignity atoms” in the case of several patients (the deficit of dignity atoms from P area can be remarkably well compensated by the dignity determined by the size of R and C or R only; the deficit of dignity atoms from R and C may be strongly compensated by P, the deficit from P, C areas by R; we cannot consider an efficient compensation of the deficit of dignity within the P, R, U area as long as the C resources are enough, because U is powerfully mediated by R). However, the type, the atmosphere, the "flavor" of these dying with dignity processes is different and they are more or less close to the actual or presumed needs and preferences of the patient in question (for example, the provision of proper body hygiene by the family members and friends, the investments in decent and varied clothes, the regular use of cosmetic products, in the case of a patient no longer capable of self-service can have a strong positive impact on the preservation of his dignity, even if most often they cannot match the amount of personal dignity derived from the situation in which the patient has functional autonomy).

The irregular shapes in Figure 2. illustrates subjective experiences of dying with dignity based on different compositions of dignity (the amount of ”dignity atoms” produced in different dimensions and the interaction between them).

The "quantity" (more or less) and/or the "type/ flavor" of dying with dignity is different for each of the six situations. The letters attached to the numbers of the shapes illustrate the dimensions where the dignity atoms come from, which, together with their quantity and their types of interactions, but also with the patient's expectation determine the quality of the dying with dignity experienced: 1-P, R, U, C (ideal composition, balanced), 2-RUC (compensation of the deficit from P area) 3-R U (compensation of the deficit from P and C areas), 4-P (compensation of the deficit from R, U, C areas), 5 – P R (compensation of the deficit from U, C areas), 6-R (compensation of the deficit from P and C, U areas).

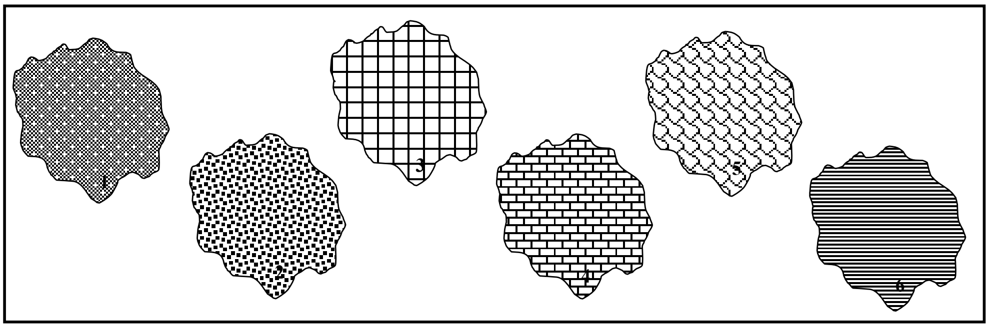

Fig. 2. Subjective experiences of dying with dignity based to different (quantitative and qualitative) dignity compositions

Throughout the dying process, according to the evolution of the illness (in terms of the variation of the patient's functional dependency degree; the need for stronger medication for pain relief, the need for special medical equipment for the maintenance of vital functions etc.) the change in dignity composition becomes necessary in order to ensure the optimal amount of dignity, as well as its quality, as much as possible (for example, the personal hygiene can be provided daily in either a humiliating manner for the patient, or naturally and respectfully).

Moreover, the optimal quantity and quality of dignity **composition** for the patient can change throughout this process, because depending on illness condition, on personality and other personal factors, on the quality of the interpersonal relations, the dying person may value at a particular time to a higher extent his functioning on the principle of hedonism (namely, the relief of loneliness, of physical pain, to be provided with massage more often, even at the price of putting more pressure on the caregivers, the significant persons etc.) and to a lesser extent on the wish fulfillment (not to be a burden, to remain dignified – distant, self-controlled -).

The bad death can be pictured by the combination of: a. *the presence of something bad and unnecessary* (pictured in the figure by the presence of the black atoms – with potential of decreasing the dignity) by *the active behavior of somebody from R* (for example: humiliation, punishment of the patient, unwanted sedation of the patient by the care providers), inadequate legislation in C (prohibition by law of the increase of the analgesics dose – in really needed situations – if they determine respiratory deficiency, which hastens the occurrence of death; bad health care policies), inadequate behavior of P (the patient's disrespectful behavior towards others, etc.); b. *the absence/ deficit of dignity atoms in any of the four dimensions,* when their occurrence is possible but did not take place, *due to certain omissions*, obviously, in the detriment of the patient (pictured by empty spaces, by the absence of a any color/ geometrical shape). For example, giving up control by the competent patient, though he would have the possibility of exercising self-determination, insufficient relief of pain when it could be accomplished, deficiency in providing hygiene or food for the patient, abandoning leaving the patient, etc.).

Figure 3a. illustrates the bad death by the predominance of the "black atoms" that decrease dignity and by the "deficit of dignity atoms", shown by empty spaces. A sample of the basic composition of the bad death is indicated by the arrow that starts from the symmetry point of the tetrahedron and illustrated "microscopically" by the irregular shape from the right side of the tetrahedron (top position). The way that the person is experiencing this is represented by the irregular shape below the first. In this case also, the experience of the undignified and/or bad death is due both to the presence of the dignity dispossessing atoms, the deficit of the dignity atoms and to the patient's characteristics and values. Figure 3b. pictures a type of bad death in which the time axis of the terminal state also holds a contribution (in this case, a to the long duration).

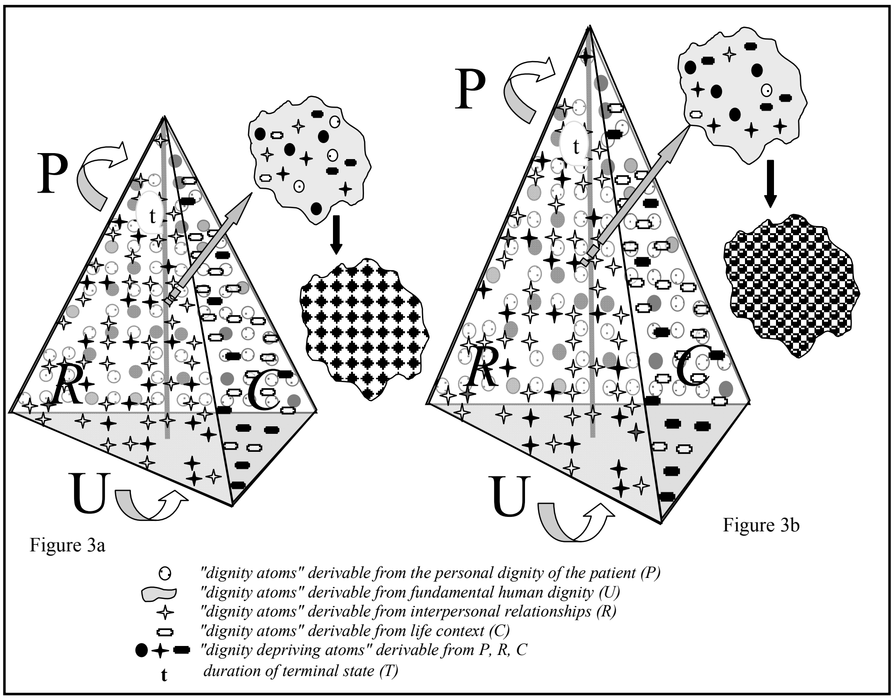

Fig. 3a and 3b: A model of bad death

Figure 4 illustrates two types of bad death: one in which the absence of the good phenomena predominate (the patient's needs are poorly satisfied, the patient is insufficiently respected, the patient is neglected) and one in which the unnecessary negative phenomena predominate (the patient is humiliated, deliberately distressed by others, etc.).

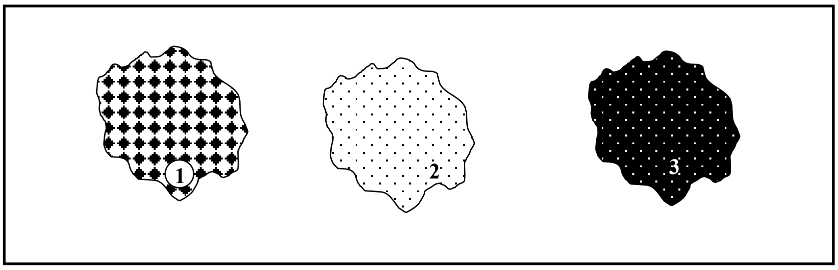

Fig. 4. Subjective experiences of bad dying due to harmed dignity based to different (quantitative and qualitative) dignity compositions

IV. General conclusions and discussions

Most of the nurses and almost half of the SSE-P descriptively defined the dying with dignity using a single element. The decreased number of responses generated by most of the respondents in the two groups is - very likely – due to the educational deficit in the field of tanatopsychology.

The acceptance of death is the element most commonly attached to the idea of dying with dignity for both the SSE-P and nurses.

Most of the SSE-P and almost half of the nurses have identified elements **involving** the patient's participation to his own dying with dignity.

The results of these pilot studies should not be extrapolated for the general population.

The conceptualization of good death, dying with dignity is deeply subjective, culturally constructed, personally negotiated by each individual. The anchors used by the individuals depend on the nature of the target group, their education, their personal experience and interests, their values.

In the daily palliative care importance is given to the approach that allows the identification (without exercising pressure on the patient) of what the good death is, what the dying with dignity means for the patient, for his family members and friends, in order to (honestly, competently, kindly, respectfully, reasonably, empathically and flexibly, culturally sensitively) support life and dying process during the terminal state.

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