

The hospice movement: the example of conflict between the process of personalized and rationalized institutionalization¹

Anna E. Kubiak²
Mária Suriková³

Institute of Philosophy and Sociology, Polish Academy of Sciences
Institute of Sociology, Slovak Academy of Sciences

The hospice movement: the example of conflict between the process of personalized and rationalized institutionalization. The article presents the problems of hospice movement in the context of the individualistic social organization, which becomes the predominant pattern of social life in the modern societies. The hospice vision focuses on the interest in the individual and his or her quality of life in the end-of-life phase, which fits the principles of individualism. The analysis of the process of institutionalization of hospice movement shows the conflict between the idealistic aim and the consequences of rationalized medical praxis. The situation of the individual as a matter of public interests is followed by temporal relationships of the hospice workers and the patient and his or her family, breaking the continuity of the natural social bonds, de-privatization of the dying, fragmentation of one's life's course and isolation of terminally ill people. These contradictions seem to be the integral part of the individualistic social organization, and as such irresolvable.
Sociológia 2010, Vol. 42 (No. 3: 237-254)

Key words: individualization; institutionalization; hospice; death; professionalization; specialization; bureaucratization

Introduction

The contemporary⁴ meaning of 'hospice' refers first of all to the place of dignified dying, where the patient is treated with holistic care. The hospice movement represents considerable contribution of modern societies to the development of social perception of the situation of people with terminal illnesses, or dying. Genesis of hospices in contemporary meaning is dated to the 19th century as a reaction to the expansive development of hospitals, where the death was not a welcome phenomenon. (Alžbeta Mračková, *Úvod do paliatívnej starostlivosti alebo z čoho vychádzame*, in: Hatoková – Mračková 2009: 12) The shift in place of death for most people in Europe and America from home to institution is the consequence of two factors. The expansion of

¹ The article was written as a part of the VEGA grant Responsibility in discourse and practice of economic actors – possibilities and limits in contemporary Slovakia (2/0156/09).

² Contacts: dr. hab. Anna E. Kubiak, Institute of Philosophy and Sociology, Polish Academy of Sciences, Ul. Nowy Świat 72, 00-330 Warsaw, Poland. Tel.: +48-22-8269946, fax: + 48-22-8267823, e-mail: akubiak@ifispan.waw.pl

³ Contacts: PhDr. Mária Suriková, Institute for Sociology, Slovak Academy of Sciences, Klemensova 19, 813 64 Bratislava, Slovak republic. Tel.: +421-2-5296 4355, fax: +421-2-5296 1312, e-mail: maria.surikova@savba.sk

⁴ Historically, the term 'hospice' was formed in Scotland, as a name of place providing the care of travellers. The notion derives from the Latin word 'hospes' identifying guest. The first institutional arrangements for refuges for the poor are among the acts of the First Council of Nicea in 325 A.D. It provided that each city should fulfil under the supervision of Deacon, situated outside the city, the place where all people in need would find a shelter.

medical technology: the use of professional equipment and the employment of skilled technicians in caring for the dying are beyond the reach of individual physicians. At the same time the mobility of modern societies has minimized the probability that relatives are available to care for an individual at the end of life. As a result, dying and the death have been relegated to professionals. The hospice movement rose from the critics⁵ of medicalization of death and the treatment of the terminally ill patients in hospitals.

The broader institutionalization of hospices and palliative care, which they offer, had begun in the second half of the 20th century – and in the post-socialist countries particularly in the two last decades. Anyway, it was in the 1980s, when the problems of maintenance of the early ideas of hospice movement were recognized. One of the main features of the structure of hospice was non-authoritarian and non-hierarchical patterns. As hospices joined the mainstream by becoming dependent on state funding, the process of professionalization, specialization and bureaucratization came in. Now hospices are even compared to the ‘total institution’ (in Goffman’s sense, 1961). As the hospices developed into multifunctional, increased in size (as a response to the pressures from institutional donors) they became formalized in their structure and relationships.

The individual, a patient with his or her own life, though ending, is the central value of the hospice movement activities. But the interest in the individual is much more general in nowadays societies, though the motives of this interest should be very different. Our aim is to present the hospice movement in the context of the individualistic characteristics of social organization, which are becoming typical and constitute fundamental part of what we nowadays call the modern societies. The focus value and the principle of the organization of social life had become the individual and the quality of his own life, while the social conditions are understood as a function of the fulfilment of the individual life. It is questionable to label the motives of the development of hospice movement as individualistic (in the sense of individualism accepted here) – they are first of all generally human; but the process of the institutionalization of this movement comes inevitably into the context of the organization principles of the contemporary societies. In this context, the process of institutionalization of the hospice movement encounters two main issues. First is the interconnection between the individual vision of the quality of the last phase of life and the rationalized institutional conditions of the medicine help (which in the palliative and hospice care does not focus on the healing, but on the management of pain). Second is the problem of the two faces of individualism (on which point out many authors, the first was already

⁵ The critical impact arose from intellectuals (psychologists, sociologists). The most famous is doctor Elisabeth Kubler-Ross.

A. de Tocqueville, the first theorist of the individualization, 1996), when society, on the one hand, puts emphasis on the value of the concrete individual, but, on the other hand, at the same time creates rationalized means and procedures with the general effect on the individual lives, by which – as a matter of fact – depersonalizes, or even alienates the individual man.

Individualistic social organization

Recently, the individualism is ever more pointed out as the social factor begetting the social development and penetrating the whole organization of social life. Individualism in this context means first of all two things: the topmost level of the value of individual (or uniqueness of man or group) in the cultures of modern societies, making “the individual” the matter of public interest; and, at the same time, it means changes of social bonds resulting in social organization creating an institutionalized social space for individual choice, self-realization and self-improvement, and also the social actions and institutions preserving and stimulating the previous.

T. W. Greene summarizes the sociological definitions as follows: “A commonly used definition of individualism is ‘socio-cultural beliefs and practices that encourage and legitimate the autonomy, equality, and dignity of the individuals’”. (Greene 2008: 117-118) In sociological discussions, individualism is often understood as a normative fact with ideological or moral origin, and ordinarily it is also *a priori* evaluated as “good” or “bad”. Individualism as a cultural fact definitely is normative, but from the sociological point of view we have to say, that its normativeness lies first of all on the supreme norm of “the individual” in social life, although, on the other hand, the exact content of this norm is in contemporary societies (and so was in history) widely discussed. Apart from the normative aspect of individualism the same importance has its structural and institutional aspect, which reflects various kinds of institutionalization of diverse social attitudes to the individual in the particular societies.

The both aspects together (cultural and structural) constitute individualism as the kind of social organization adopted in modern societies, in case that we define social organization as the purposive rational orderliness of social relations between the elements of society. (Pichňa 1998: 24) There has to be said, that not the whole of social life in complex societies is organized by the one common criterion, but there is a tendency to make an individualistic principles central for organizing the more and more spheres of social life. Whereas the ideological basis of individualism were created mainly in the Enlightenment philosophy and politically were adopted in the 19th century, the second half of the 20th century is regarded as an era of institutionalized individualism, in which the individual became in a big degree socially

autonomous and the sphere of private life in comparison to the traditionally public sphere has broaden even more. G. Lipovetsky characterizes the 1960s as the second individualistic revolution (for distinction of the Enlightenment roots of individualism). (Lipovetsky 2003: 7)

The first period of individualization was philosophical and political process, creating a social definition of the 'individual' and the ideological basis for the constitution of social space for one's autonomous social self-realization. The second period, dated in the second half of the 20th century, is characterized by the institutionalization of the individualizing social mechanisms. The new, individualistic principles have spread also into the organization of the social movements, which are reflected in the distinguishing of the so-called new social movements. The features of their difference are the broad, heterogenic sources of the recruitment of members; growth of their political importance; promotion of universal values and human rights, especially protection of the minorities and the weak.

The hospice movement presents itself as the reaction to the equivocal social attitudes towards terminally ill and dying people after the transfer of ill and dying people from home to the hospitals, where death was considered as a failure of medical care and solutions of the problem were heading for the institutionalization of the euthanasia. The hospice movement points out that there is need for social institutionalization of the new conditions of death and dying since for a long time it is not just the problem of the family or the local community any more.

Social interest in the individual leads to the broadening of the private sphere in the individualistic organization of societies, which is closely interconnected with the vanishing of the clear boundary lines between private and public sphere. There is not so much the perishing of social, the retreating of society from individual lives or even de-socialization, as some analyzes suggest, but much more the focusing of the society on the individual and his life without any authoritative intentions. Social emphasis on individual freedom, stimulation of individual uniqueness, and upholding more helping or therapeutic position of authorities in the process of social regulation brings public interest on particular situations of individual life, and the individual decease is one of them. Although, the issue of dying people was always the matter of public interest, the individualistic focusing on the individual and his or her life brings public interest on particular traits of one's death.

The hospice vision is attuned with the present individualistic social organization requirements of general concern with individual. As Zygmunt Bauman puts it: "Casting members as individuals is the trademark of modern society." (Foreword ... in: Beck, Beck-Gernsheim 2001: xiv). Modern societies try to engage persons not so much through their adaptation to social roles and

positions, which they occupy in the social relations and bonds, but focus on the person him or herself and treat the social milieu as something that should cope with the needs and requirements of the individual. This general humanism is a source of constituting of diverse social institutions and movements specialized in the developing of the life conditions of individuals. After the withdrawal of the common religion from the centre of the social moral life, the ‘fulfilling life’ of the individual became the crucial value in modern societies. At the same time, this value has highly personalized content – it presupposes that only individual can recognize what is fulfilling his or her life. That is why the current feature of the social institutions and movements is their therapeutic function: they make effort to look operating not as administrators of the authority, but as helpers for individuals to find what they really need and want. (See e.g. Fukuyama 2000)

History and current development of hospice movement

Cicely Saunders (1918 – 2005) led the establishment of the modern hospice movement. After training as a nurse, she took a position in an oncology unit at St. Thomas’s Hospital in London. She met David Tasma, a Polish Jew, separated from his family and country. Reflecting on his situation spurred Saunders to ask what she could do to relieve the suffering and meet the needs of others like him. As her interest matured, Saunders volunteered at St. Luke’s in Bayswater, a well-established home for the dying. Here, she noted that pain-killing drugs were given at regular intervals instead of waiting until the pain returned. Also, whenever possible, injections were avoided and drugs were given orally, a method that was easier for patients and for family members caring for patients at home. These basic principles later became fundamental in hospice care. She soon began studies that led to her medical degree. After qualifying in April 1957, Saunders obtained a research scholarship in pain research at St. Mary’s Hospital and began to implement her ideas at St. Joseph’s Hospice, Hackney. Before long, she determined to organize a body of like-minded supporters, develop a plan for an independent hospice facility, raise money, purchase a site, and build the new facility. St. Christopher’s Hospice in southeast London opened in 1967 as a purpose-built, inpatient facility designed to implement the new goals of excellence in clinical practice, research, and education in care of the dying. “St Christopher’s became not a model hospice, but the model hospice, ‘the final step in synthesis of the modern form of hospice’ in Britain and throughout the world.” (James 1996: 109)

Subsequent developments of the hospice movement in England took many forms. They include additional free-standing, inpatient hospice facilities (often purpose built); other inpatient hospice facilities built with private money on the grounds of National Health Service (NHS) hospitals and then operated by the

NHS; palliative care or continuing care inpatient units within some NHS hospitals; hospice home care teams developed to support the work of general practitioners and district nurses; hospital support or consultation teams to advise on the care of the dying in acute care hospitals; and hospice day care programs.

In the 21st century, there are hospice and/or palliative care initiatives in 115 countries. For about 25 years, the World Health Organization has sought to foster hospice/palliative care, improve professional education in this field, remove legal sanctions against opioid importation and use, and disseminate core principles of pain management. In Canada, palliative care services were first developed at St. Boniface General Hospital in Winnipeg and at the Royal Victoria Hospital in Montreal in 1974. A broad variety of nearly 500 programs and services offering hospice palliative care have been developed across Canada, along with several provincial associations and the national Canadian Hospice Palliative Care Association.

In the United States, hospice care began in September 1974 with a community-based home care program in New Haven, Connecticut. From this beginning, hospice care has spread across the country. In 2005, the National Hospice Care Organization (<http://www.nhpco.org/>) estimated there were 4,160 operational hospice programs in all 50 states, the District of Columbia, Puerto Rico, and Guam. Hospice programs in the United States are organized in many ways. Most are independent, free-standing agencies; others are hospital based, divisions of home health agencies, or based in long-term care facilities. Approximately two-thirds of hospice programs in the United States are non-profit in character; the remainder are for-profit or government organizations. Nearly one-fifth have their own inpatient facility.

In Poland the hospice movement started in 1981, when The Friends of the Sick Hospice Society was founded. The first hospice started in Gdansk (in 1984), then in Poznan (in 1989). The first hospice for children was founded in 1996 in Warsaw. Now there are about 160 hospice programs in stationary hospices, home-based care and the departments of palliative care in hospitals. In Poland most of the hospices are connected with the Catholic Church.

29 of August 2009 Ministry of Health published the regulation about the guaranteed palliative and hospice care (on the basis of article 31, the Act of 27 August 2004) on allowances for guaranteed funded care. Benefits are realized in conditions:

- 1) in stationary hospices;
- 2) in home hospices;
- 3) in the branch of palliative medicine.

Guaranteed implements in stationary hospices include:

- 1) provision of health care provided by doctors;

- 2) provision of health care provided by nurses;
- 3) pharmacological treatment;
- 4) treatment of pain;
- 5) treatment of other somatic symptoms;
- 6) psychological care;
- 7) rehabilitation;
- 8) preventing of complications;
- 9) medical supplies.

In Slovakia, the first, unsuccessful attempt to establish a hospice facility, St. Martin's Dome, came from the NGO – Foundation Hospice in Martin. (Potocký, 2002) The first department for palliative care in state hospital was established in National Oncological Institute in Bratislava in 1995. In Slovakia, the hospice initiative have come both from the church and the non-church NGO's, what caused a duality diluting the advocacy of the need to include the hospice care to the state health policy and supported the predominating medical attitudes, although the death is not just a medical problem, but also the social and the societal. (Fabuš 1999) The legal situation has changed in 2000 and the first Conception of palliative care was approved by Ministry of health of Slovak Republic in 2002 – and the first hospices were established in 2002: Mother Theresa's Hospice in Bardejovská Nová Ves and Children's hospice Plamienok in Bratislava. Since then the various forms of hospice care (inpatient, stationary, mobile, palliative departments in hospitals) were spread across the whole Slovakia. Slovak Association of hospice and palliative care was founded on 13th June, 2000. The first cycle of Bereavement Training Course for specialists, accredited by Ministry of Education took place in Plamienok – Slovak Hospice for Children Educational Centre for Paediatric Palliative Care in Bratislava since April 2009 to January 2010.

Since 1st July, 2006 the new Conception of health care in the specialty of palliative medicine including hospice care is in effect. It acknowledges the international value, legal and institutional development of palliative and hospice care; defines the palliative and hospice care – its forms and personnel characteristics; specifies patients with the claim to palliative or hospice care; regulates the cooperation with the other medicine specialties, sets the professional and methodical administration of palliative and hospice care; ordains the system of control; and lays down the developmental trends and conditions for the education of the health personnel in the specialty. (See Koncepcia...) The inclusion of the palliative and hospice care into the system of the public insurance is evaluated very positively by the specialists in regard to its accessibility and development.

In Poland and Slovakia the national conceptions of the hospice and palliative care are inspired and even recommended also by the international

institutions. Along with the World Health Organization, there are the recommendations and the documents of the authorities of the European Union (the basic ones are Recommendation 1418 (1999)¹ Protection of the human rights and dignity of the terminally ill and the dying and Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care). Worth of mentioning is also the Poznan declaration about palliative care in the East Europe (1998). In 1988 the European Association for Palliative Care was founded. (See Koncepcia...)

The Recommendation 1418 (1999)¹ of the Council of Europe on Protection of the human rights and the dignity of the terminally ill and the dying identifies the factors, which threaten fundamental rights deriving from the dignity of the terminally ill or the dying people as follows:

- “insufficient access to palliative care and good pain management;
- often lacking treatment of physical suffering and a failure to take into account psychological, social and spiritual needs;
- artificial prolongation of the dying process by either using disproportionate medical measures or by continuing treatment without a patient’s consent;
- the lack of continuing education and psychological support for health-care professionals working in palliative medicine;
- insufficient care and support for relatives and friends of terminally ill or dying patients, which otherwise could alleviate human suffering in its various dimensions;
- patients’ fear of losing their autonomy and becoming a burden to, and totally dependent upon, their relatives or institutions;
- the lack or the inadequacy of a social as well as institutional environment in which someone may take leave of his or her relatives and friends peacefully;
- insufficient allocation of funds and resources for the care and support of the terminally ill or dying;
- the social discrimination inherent in weakness, dying and death.”

(Protection of the human rights...)

Hospice Vision

Hospice care is a form of end-of-life care designed to minimize the sources of pain and distress, improve quality of life, and offer opportunities for growth. Hospice vision is based on the idea that dying is a normal part of the life cycle, that opportunities for growth are possible when nearing the end of life, and that the quality of an individual’s life is more important than the duration of one’s life. Hospice views the patient and family as the unit of care and promotes

patient decision-making, with patients and their families participating actively in the care planning process.

Efforts to achieve a high quality of life stress the importance of physical, emotional, and spiritual comfort and the respect for one's dignity. The care plan for a hospice patient and his or her social support network provides holistic care, or care for the needs of the "whole person": physical, psychological/emotional, social, and spiritual. Psychological/emotional care focuses on meeting the basic psychological and emotional needs of the patient, assisting the patient and his or her support network in coping with the patient's impending death, and to facilitate communication about any unresolved problems that can be addressed. Spiritual care assists the patient and family in finding meaning and purpose in the remainder of the patient's life, discussing beliefs about what happens after death, and assisting the survivors in coping with the death of the patient. "The enlightenment of listening with the dying and hearing their manifold needs had a significance and power for early hospice planners that should not be underestimated. But part of the strength of 'the vision' derived from the positive, active caring which contrasted with fear and concern at the impersonal management of death." (James 1996: 104)

In the early part of the 20th century, dying in a hospital was limited to those without financial or social resources. Sick individuals with sufficient resources recovered or died at home, among family and friends. The current attitude toward preferable place of death, reflected in polls showed that for example 70 % of Americans and 68 % of Poles wanted to die at home. In reality most people (75 % of Americans) die in medical institutions. The founder of the hospice movement recognized the need for the integrated care, which is established by the last researches as one of the main trends of changes in the organization of the care service in general: erasing of the dichotomization between home and residential care, formal and informal care and between health and social care. (Repková 2007: 15-16)

The hospice vision implicitly presumes the processes, which Dilbar Alijevoá has named the processes of social making significant (or making meaningful), which she suggests to use as the process instead of the static category. Those processes reflect the role of the community in relation to the individual self-conception and evaluation of the meaning of his or her experience and whole life. They point out on the interconnection of the personal evaluations of the meaning or meaninglessness of one's life, its parts or his or her personality with the social evaluation processes. "It can be said, that during his life cycle one stepwise "fulfils" his self-conception with the due meanings, by sum of which he gets to the experience of his significance in the broader social context. In this regard the making significant cannot be reduced only to the ascribing (to the individual) the meanings with manifold, either

positive or negative content, but presupposes rather dimension of significance or graduating significance of the person of the individual during his whole-life course.” (Alijevova 1994: 208)

The processes of social making significant or making meaningless are intrinsically connected with the individualization of the modern societies through the mechanisms of the reflexive social reordering. Alijevova stresses the problem of the making meaningless the experience of whole, first of all the older generations. (Ibidem) Although the motives of the processes are chiefly historical and ideological, in contemporary societies the old and ill people lost much of their social contribution. The development of communicative technologies and the circulation of information relegated the elderly from the position of the intelligence authority; the institutionalization of the retirement, the insurance system and the constitution of the nuclear (instead of the multigenerational) family changed their position in society from the helpers in the family to the social burden. In this regard, the hospice vision points on the process of isolation and social marginalization, particularly of the dying and death through the reductive medicinization of illness and dying and tries to persuade and show that terminal illness and dying are the significant phases of the patient’s life and should be supported by the broader society (e. g. by insurance systems, but first of all by integration of the ill and dying to their social milieu).

Institutionalization of hospices

In the modern societies the perception and conditions of illness and dying have changed. They are not primarily interpreted in the religious and moral context, but much more in the context of plenitude, satisfactoriness and personal expectations towards the earthly life. There are also the new strategies of social preparation to the handling the illness and death: the respect for the religious and moral authorities has felt and the interest in personal experience and common sharing became the credible guideline form. In addition, there is a strong cult of youthfulness and technicality in the social attitudes towards human physical, and generally life condition (including illness and dying). The increase of social interest in human body and medicalization of some social problems is one of the guiding phenomena of the individualistic social organization.

Distinctively has to be mentioned the specific cultural concern with the human body. The state of the body became the important social norm: the demonstration of individual originality and authenticity and even the important factor of social differentiation. Gilles Lipovetsky arguments how the “cult of human body”, embraced and institutionalized as a component of individualism, leads to the social contradiction: there is the public eagerness for exposure of

intimacy, the narcissistic forms of social subsuming, but at the same time raises the ambivalence towards the death of the particular people. (Lipovetsky 2003) In fact, the interest in the body and the dying emerge from the importance of the social processes of the establishing the norms for the physical life and the state of the body in the individualistic social organization. The meaning of those norms is highly subjective, not social/relational – there is not the ill or dying person in the centre of the public attention, but his or her personal experience. This is the root impact of the individualism on the social life: the overestimated interest in everything what is individual, and at the same time the social marginalization of the concrete person and his or her life situation.

“The early hospice vision emerged from individuals’ personal convictions to become a descriptive ideal, dedicated, critical of former practice and with the intention of disrupting former patterns of care of dying. Committed to listening to patients, to perceiving death as time of growth, to offering an alternative to euthanasia by providing skilled, compassionate care for people dying of cancer, hospice aspirations were on a grand scale and the need for ‘the vision’ to be taken up was pressing. Nevertheless, the success of this proselytizing could hardly have been anticipated.” (James 1996: 111)

It was in the 1980s, when the problems of maintenance of the early ideas were recognized. There was a criticism toward focus on cancer patients, although it changed with AIDS epidemic. (Wald 1996: 88) There were financial difficulties, problems with regular staff turnover, ‘burning away’ of nurses, sort of people, who just needed a job, lack of volunteers, reputation as ‘a place where people die’, routinization and professionalization. The lack of financial recourses for a good education resulted in disappearing preparatory courses for a new staff. The demand of the medical diploma in palliative medicine has been abandoned in many units. “In the early years of the modern hospice, the idea that staff would be ‘friend’ or ‘family’ if that was required, was strong.” (James 1996: 123) Now ‘befriending’ is recognized as an expensive, optional extra. “Traditionally the biomedical system emphasizes the physical. Hospice services which initially strived for a balance of ‘total care’ may observe the primacy of physical interventions re-emerge” – notices James. (1996: 123)

Competing for funds is another factor that led them to become more professional and bureaucratic. “Many hospice organizations have expanded as a consequence of their success, treating more patients, widening the range of their activities, and recruiting more staff. This may mean they become more formal and bureaucratic in order to cope with the additional activities and pressures.” (Field, Johnson 1993: 204)

The hospice movement broadens the problematic of specialized health care from the physical extend to the totality of patient’s life. Saunder’s concept of

‘total pain’, which embraces all four mentioned aspects of patient’s pain – physical, psychological, social and spiritual – enables to detach the end-of-life phase as a socially defined independent phase of human life. The same social process of fragmentation of individual life cycle through detaching its particular sequences, which was historically preceded by the social detachment of the phases of childhood and the elderly, is now under way to finish the detachment of this – the latest – phase of life. The detachment proceeds on the level of social significance and rounds off on the level of the institutionalization of the style of life.

In all countries the problem of the relationship between the medical health service systems and the institutionalization of the hospice and palliative care arises. These phenomena can be analyzed as the problem of different social interpretations of the social engagement or competencies to enter the social environment of the patient. The main competence of the hospice care is its specialization, which exceeds the abilities and the possibilities of the patient’s family. On the other hand, the specialized hospice workers and volunteers come into a kind of a “pure relationship” (Giddens 2002) with the patient and his family. As Giddens characterizes it, the “pure relationship”, in opposite to the personal bonds, is not rooted in the outside conditions of the social life, mainly through the system of the rights and obligations, which overrun the content of the relationship alone – it serves first of all to the emotional and personal satisfaction and its functionality is reliant on this satisfaction. The “pure relationship” works like the reflexively structured relationship with an open and continuous character, its aim represents the relationship alone. In the “pure relationship” the main role plays the devotion, mutual being together. The intimacy and the mutual trust in the relationship decide about its stability and the trust has to be won, because one can hardly stake a claim for it on some social basis. In the “pure relationship” one finds the confirmation of his or her own identity and the bonding element of the relationship is the history of the relationship. (Giddens 2002: 124-136)

The “pure” character of the specialized care relationships leads to the institutional problems. The main bunch of problems is caused by the holistic enclosure of the relationship to the patient or the patient’s family. The holistic orientation of the hospice care has tendency to create such a pure character of the relationship between hospice workers or volunteers and the patient or patient’s family. Evidently, the constitution of the relationship of the kind of “pureness” has the consequences in managing the hospice activities into the two institutionalized tracks – either it is rationalized (and creates the bureaucratic organizations with broad range), or becomes just the temporary activity dependent on the personal satisfaction of the involved.

The last one can be avoided by the integration of the hospice care to the social welfare system, for which usually call the hospice keepers. But the opposite side of this integration is the increase of the first problem. On the other hand, the problem of bureaucratization can be avoided by the creation of the more informal relationship structures, in which the hospice care could be realized. But then the problem of the incorporation of the hospice care to the natural social environment of the patient arises. That mean, that the boundedness of the hospice care to the social situation of the terminal illness or dying of the patient has to be struggled.

The problem of this contradictory is much broader and refers not only to the hospice and palliative care, but to the whole welfare state. At the same time, when the problems have been recognized in the functioning of the hospice care, the crisis of welfare state became the issue of the theoretical discussions. The three main domains of the need for change of the social politics in modern welfare states have been identified: financial (there is the critique of the unsustainable increase of state expenses); legitimacy (there is the opinion, that the politics promoting principles of social solidarity and cohesion, and “egalitarian” politics and politics equalizing social differences lost its legitimacy and support of the citizens); and institutional (which is connected with the critique and rejection of the state centralization and excessive bureaucratization of the system of welfare state and its institutions). (Čambáliková 2009: 33) Evidently, the key problem is to what extent and in which sense the individual can be the object of the public or even state interest.

‘The loneliness of the dying’

In this perspective the development of the hospice movement can be seen – apart from its specialist medical function – also as a creation of the alternative social space for dying accepting the functions which were in the former history held by the complexity of the social environment of the individual. But this alternation seems to have the similar problems as the other types of the alternations of the basic forms of social life (for example the alternations of the marriage and the family life) – this is the dealing with the lack of broader social commitments maintaining the lasting of the relations and fulfilling their functions, and also providing the experience of the personal dignity based on the personal relations instead of constructed ones.

Hospice movement offers guiding for the terminally ill or dying person as a kind of steering people by way of personal relationship. But the content of this steering is the activation of the personal sources of the ill or dying person. The hospice movement develops activities motivating people for the active life in this phase of their life, which became socially and in consequence partly also psychologically emptied. The method of the hospice workers is based on the

listening and respects the individuality of the terminally ill or dying person. There is no standardized way of guiding or the expected effect of guiding apart from the personal relationship between the patient and the volunteer or hospice worker.

The aim of the hospice activities is to create a specialized social milieu of the patient or to bring to his own family the specialists focusing on the patient and his needs which are the consequences of his illness. Chiefly their activities are concentrated on the increasing of the significance of the ill or dying person in his or her own eyes in result with his or her experience of the dignity.

In this way the hospice movement reacts to the main contradiction of the individualistic social organization: it is trying to connect the social interest in the quality of life of the particular person, making it significant, with the specialization, which penetrates the boundaries of the private life. The process of specialization works here as an instrument of the individualization in two senses: it isolates ill and dying people from their natural social milieu and deprivatizes the situation of individual dying as a matter of public interest.

Ulrich Beck and Elisabeth Beck-Gernsheim use for the illustration of the structural effects of the specialization the metaphor of economical process of an outsourcing: „...there is a generalized outsourcing of functions, of operations. The hierarchical economic organization begins to regularly make decisions, not to ‘make’ but to ‘buy’. A whole host of functions of the firm are outsourced in this age of vertical disintegration. The welfare state begins to outsource functions onto private and charitable sector organizations. It seems that there is also an outsourcing of the family.” (Beck, Beck-Gernsheim 2001: x) This process of “outsourcing”, or the transfer of some social functions and competencies to the more global instances goes hand in hand with the process of “insourcing”, or subjectivization, which displace some social functions and competencies intensively, onto the individual. (See *ibidem*) This causes the very well known social effect of the individualized deprivatization, when the interests and the motivations of the individual gain the political or public character. Anthony Giddens calls this phenomenon the politics of life, which he sets apart from the politics of emancipation. “This is the politics of self-realization in the reflexively ordered environment, where the reflexivity connects the identity and the body of the individual with the systems of the more global extent. ... The politics of life is – I underline – the politics of the life decisions.” (Giddens 2002: 292) The term politics of life emphasizes the significant dynamic role of the public opinion and public processes of decision-making for the lives of individuals.

Considering the structural level, the hospice movement offers sources, which are attractive, both for the state with its social care or welfare system, and for the terminally ill or dying people and their families. From the state

point of view, the hospice workers provide the specialist care for patients, what corresponds with the concern with the individual human rights, applied also to the situation of terminal illness or dying. But the position of the terminally ill or dying person, and his or her family, is different. The classic Elias' (1985) work about the modern processes followed by social isolation of the dying is still the adequate description of the contemporary scene. The icon of "a dying person connected by tubes and wires to life-sustaining equipment" (Gill 2004: 154), being a derivative of bureaucratic and technological surrounding, is powerful.

As the research of Gill (2004) shows there are good examples of 'sympathetic professionals', mainly volunteers. They use the strategy of "individualization and personalization of the patient/family". (Gill 2004: 156) They are the active human agents, who shape the care for dying patients. But generally – as the author admits – "a decent and fulfilling human life" (Gill 2004: 153) dying is a utopian image.

In some way, the hospice workers and volunteers are trying to substitute or to supplement the patient's natural social milieu on the principle of the holistic care for the patient and his or her motivation to the continuing personal growth. This orientation makes the hospice movement the genuine institution of the individualistic social organization: it deals with the problems originated from the development of the individualism and follows the cultural principle of the total and authentic individual. One of the root problems of individualistic social organization, on which pointed out Jean-Claude Kaufmann (2004), is that the individual represents very bad holder of the realization of the holistic enclosure, since individual is not definite category of social structure and creates himself in the relationship with the social (and other) environment. (Kaufmann 2004: 246) The detachment of the end-of-life phase as the different phase of individual life does not mean just the special social interest in the situation of the temporal illness and death or professionalization of the specialist social environment for this situation, but it carries also the burden of the breaking of the continuity of the social milieu and in consequence the social isolation of the terminally ill or dying person. The hospice movement reveals the cultural contradictions in the social attitudes to the death and dying. The seed of those contradictions is the problem of how to fit together the general cultural conviction about the rights to quality of life in the end-of-life situation with the diminution or the lost of social functions of terminally ill or dying people.

Conclusions

The reality seems to challenge the vision of the founders of the hospice movement, mainly the idealism of the concept of the patients' total pain, which

represents the key idea in the hospice functioning. But the problem could be seen reversely – as the challenge for the vision of the correctness and rightfulness of the individual life and his or her experience as a matter of public interest.

The aim of holistic care – physical, psychological/emotional, social, and spiritual can be comprehended as the call for fuller connection of those spheres of life on the societal level (not only in the “pure relationship” between hospice workers and the patient and his or her family). The vision of the holistic care is legitimate as the ideal and probably can be realized, when the problem of the “alternation” of the genuine social milieu by hospice workers would be solved in the level of the broader social organization. That means, that society would have clear notion about the sense of the presence of terminally ill and dying people amongst us (with spiritual and psychical impact to their end-of-life situation), and that this notion would be constitutive for the real (in comparison to the “pure”) social relationships and bonds.

Despite the cultural process of renaissance of death, the social consciousness of death and dying is marginal. In the secularized and individualized society there is a lack of rituals of dying. According to the theory of “rites of passage” (van Gennep 2006) moving to hospices is only the first step: exclusion of dying⁶. It leads as to the general problem analyzed by Michael Foucault (2002): bio-power. In this context hospices are instruments of bio-power, which cultivates youth, health and body.

Despite many efforts to minimize the medicalization in the last phase of life it is the strong fundament of western culture. Traditional societies condemned to death and allowed to live. Modern societies demand to live and allow to die. Bio-power comprehends a medical practice by normalization, rationalization and commercialization processes. Its subject is a population, not an individual human being. In the consequence, hospices seem to be only the better version of hospitals.

Anna E. Kubiak is a cultural anthropologist, dr. hab. She is working as a researcher in the Institute of Philosophy and Sociology, Polish Academy of Sciences and as a lecturer in Collegium Civitas in Warsaw. She is the author of books: *Delicacy and the Left Krishna's Hand* (IFiS, Warsaw 1997), *However NEW AGE* (Santorski & Co, Warsaw 2005), *Nostalgia and other longing* (Stopka, Łomża 2007). Currently she is conducting research on death in social space and public discourse.

Mária Suríková is the absolvent of the sociology. The Faculty of Humanities, Trnava University. She works as the research fellow in the Institute of

⁶ According to van Gennep there are following steps in the rituals of passage: exclusion, marginality and inclusion.

Sociology, Slovak Academy of Sciences and a lecturer on the universities in Slovakia. Her main professional interest is the individualization and its social implications.

REFERENCES

- ALIJEVOVÁ, D., 1994: Zbežvýznamňovanie ľudského života ako generačný problém. *Sociológia* 26, nr. 3, pp. 207-216.
- Asociácia hospicovej a paliatívnej starostlivosti Slovenska. Paliatívna medicína a liečba bolesti, 2008, vol. 1 (1): 40.
- BECK, U. – BECK-GERNSHEIM, E., 2001: Individualization. Institutionalized Individualism and its Social and Political Consequences. London-Thousand Oaks-New Delhi: SAGE Publications.
- ČAMBÁLIKOVÁ, M., 2009: Sociálny štát: občianstvo, práva, začlenenie. Sládkovičovo: Vysoká škola Visegrádu s.r.o., Vysoká škola v Sládkovičove.
- ELIAS, N., 1985: *The Loneliness of the Dying*. New York, London: Continuum.
- FABUŠ, S., 1999: Vývoj Hospicového hnutia na Slovensku. <http://www.hospice.cz/vyvoj.html>, 10. 2. 2010.
- FIELD, D. – JOHNSON, I., 1993: Volunteers in the British hospice movement. In: Clark, D. (ed.), *The Sociology of Death: Theory, Culture, Practice*. Oxford: Blackwell. Pp. 198-220.
- FOUCAULT, M., 2002: *Historia seksualności*. Warszawa: Czytelnik.
- FUKUYAMA, F., 2000: *Wielki Wstrząs. Natura ludzka a odbudowa porządku społecznego*. Warszawa: Politeja.
- GENNEP, A. van, 2006: *Obrzędy przejścia*. Warszawa: PIW.
- GIDDENS, A., 2002: *Nowoczesność i tożsamość. „Ja” i społeczeństwo w epoce późnej nowoczesności*. Warszawa: Wydawnictwo Naukowe PWN.
- GILL, E., 2004: Between Organizations, Family & Death: Caring Creatively within the Hospice Organization. In: Cruz, L. (ed.), *Making Sense of Dying and Death*. Oxford: Interdisciplinary Press. Pp. 153-161.
- GOFFMAN, E., 1961: *Asylums*. New York: Anchor Books.
- GREENE, T. W., 2008: Three Ideologies of Individualism: Toward Assimilating a Theory of Individualisms and their Consequences. *Critical Sociology* 34. Pp. 117-137.
- HATOKOVÁ, M. – MRAČKOVÁ, A. (eds.), 2009: *Sprevádzanie chorých a zomierajúcich. Dobrovoľníctvo v nemocniciach a paliatívnych zariadeniach*. Bratislava: Don Bosco.
- JAMES, N., 1994: From vision to system: the maturing of the hospice movement. In: Lee, R., Morgan, D. (eds.), *Death rites. Law and ethics at the end of life*. London, New York: Rutledge. Pp. 102-130.
- KAUFMANN, J.-C., 2004: *Ego.Socjologia jednostki. Inna wizja człowieka i konstrukcji podmiotu*. Warszawa: Oficyna Naukowa.
- Koncepcia zdravotnej starostlivosti o odbore paliatívna medicína vrátane hospicovej starostlivosti. [Http://hospice.sk/hospice1/index2.php?id=324](http://hospice.sk/hospice1/index2.php?id=324), 28.4.2010.
- LIPOVETSKY, G., 2003: *Éra prázdnoty. Úvahy o současném individualismu*. Praha: Prostor.

- PICHŇA, J., 1998: Sociológia podniku. Trnava: 3. revised edition. Fakulta humanistiky Trnavská univerzita v Trnave v spolupráci s vydavateľstvom Petrus.
- POTOCKÝ, P., 2002: Ako ďalej v Hospicovej starostlivosti na Slovensku? <http://www.hospice-martin.szm.com/publikacie/Ako%20dalej%20v%20Hospicovej%20starostlivosti%20na%20Slovensku.html>, 10. 2. 2010.
- Protection of the human rights and dignity of the terminally ill and the dying. Recommendation 1418 (1999) 1, Parliamentary Assembly, Council of Europe. (Extract from the Official Gazette of the Council of Europe – June 1999). <http://assembly.coe.int/Documents/AddoptedText/ta99/EREC1418.htm>, 28.4.2010.
- Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care. [http://www.coe.int/t/dg3/health/Source/Rec\(2003\)24_en.pdf](http://www.coe.int/t/dg3/health/Source/Rec(2003)24_en.pdf), 29.4.2010.
- REPKOVÁ, K., 2007: Rodinná starostlivosť na Slovensku ako verejný záujem. Bratislava: Inštitút pre výskum práce a rodiny.
- TOCQUEVILLE, A. de, 1996: O demokracii w Ameryce. Kraków: Wydawnictwo Znak.
- WALD, F., 1996: The Emergence of Hospice Care in the United States. In: Spiro, H., Curnen, M., Wandel, L. (eds.), Facing Death. Where Culture, Religion and Medicine Meet. London: Yale University Press, New Heaven. Pp. 81-89.