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END-OF-LIFE CARE IN GERMANY

An overview

The grounding obligation of medicine, in general, and pain medicine, by extension, is to the intrinsic dignity of the individual. It is the basis for establishing medicine as a curative, healing and caring profession with an objective moral responsibility to respect the sanctity of life and vulnerability imparted by disease, illness, and suffering. These vulnerabilities occur in unique, individual persons and are manifested through decrement in physical, psychological and social integrity, and a demise of personal station. The treatment of particular diseases, illnesses, and suffering so to preserve or restore personal dignity is the temporal obligation of the practice of medicine¹.

Just in this sense as James Giordano excellently embodied it has all end-of-life care to be directly determined by the person of the dying human being. The dealings with him should, at every phase, be of a quality that ensures his being perceived as a person². This applies especially if he is no longer capable of action or decision-making himself.

¹ J. Giordano, *Pain Care at the End of Life. Preserving Dignity*, „Pract. Pain Management” 6,3 (2006), p. 68.

² Cf. idem, *Toward a Moral Grounding of Pain Medicine: Consideration of Neuroscience, Reverence, Beneficence, and Autonomy*, „Pain Physician” 11 (2008), p. 7–12; J. Giordano, J.C. Engebretson, R. Benedikter, *Culture, Subjectivity, and the Ethics of Patient-Centered Pain Care*, „Cambridge Quarterly of Healthcare Ethics” 18 (2008), p. 1–10; Y. Maricich, J. Giordano, *Pain, Suffering, and the Ethics of Pain Medicine: Is a Deontic Foundation sufficient?*, „American Journal of Preventive Medicine” 17,1 (2007), p. 44–65.

To perceive him as a person, or, to use a term of ours, as a subject or a subjective „self”³, is not possible if we consider him isolated and in an abstract manner. In contrast, we have to become aware of the network of actions of which he, directly and indirectly, forms a part, and in which we encounter him and in which he appears. The variety and complexity of this network of actions corresponds to the multitude of perspectives from which he is being seen and perceived⁴. The different perceptions allow us, at the same time, to convey certain characteristics of the end-of-life care in general in a certain country, in this case Germany. This is why the short overview of end-of-life care in Germany will be undertaken with the different perspectives in which the dying human being themselves, or, more specifically, the palliative patient, are being perceived or described. This does of course involve perspectives of various natures, systemic perspectives, perspectives of action, personal perspectives, the ultimate one necessarily being the patient’s own. Considering that, I would like to give a short characterisation of perspectives that taken shape in Germany:

- the epidemiologic and statistical perspective
- the perspective of the providers of hospitals and finance
- the social-political and medical ethical perspective
- the perspective of the person affected and their relatives⁵.

³ Cf. J. Giordano, N.B. Kohls, Spirituality, Suffering and the Self, „Mind & Matter” 6,2 (2008), p. 179–191.

⁴ Cf. the thoroughgoing studies: J. Giordano, M.E. Schatman, *An Ethical Analysis of Crisis in Chronic Pain Care: Facts, Issues and Problems in Pain Medicine*, part 1, „Pain Physician” 11 (2008), p. 483–490; J. Giordano, M.E. Schatman, *A Crisis in Chronic Pain Care: An Ethical Analysis*, part 2: *Proposed Structure and function of an Ethics of Pain Medicine*, „Pain Physician” 11 (2008), p. 589–595; J. Giordano, M.E. Schatman, *A Crisis in Chronic Pain Care: An Ethical Analysis*, part 3: *Toward an Integrative, Multi-disciplinary Pain Medicine Built Around the Needs of the Patient*, „Pain Physician” 11 (2008), p. 775–784.

⁵ The following analyses of the state of end-of-life care in Germany is based on: *Bundesarbeitsgemeinschaft*, in: *Ambulante Hospizarbeit. Grundlagentexte und Forschungsergebnisse zur Hospiz- und Palliativarbeit*, Teil 1, ed. Hospiz e.V., Wuppertal 2004; *Stationäre Hospizarbeit. Grundlagentexte und Forschungsergebnisse zur Hospiz- und Palliativarbeit*, Teil 2, ed. id., Wuppertal 2004; Deutscher Hospiz- und Palliativ Verband, *Ambulante Hospizdienste und stationäre Hospize vor existentiellen Problemen – Neureglungen dringlich (13.03.2009)*, in: http://www.hospiz.net/stamhole/pdf/stellung_neu_39a-sgb5.pdf; C. Müller-Busch, *Palliativmedizin im 21. Jahrhundert – Was tun? Was unterlassen?*, „Zeitschrift für Palliativmedizin” 1 (2000), p. 8–16; C. Müller-Busch, I. Anders, T. Jehser, *Wie viele Palliativstationen und Hospize brauchen wir in Deutschland?*, „Zeitschrift für Palliativmedizin” 2 (2001), p. 16–19; C. Müller-Busch, *Palliativpatient – wer ist das?* (3. Petersberger Gesundheitssymposium „Palliativmedizin: Herausforderung für das Gesundheitssystem”, 01. Juli 2004; Deutsche Hospiz Stiftung. HPCV-Studie: Hospizliche Begleitung und Palliative-Care-Ver-sorgung in Deutschland 2008, in: http://www.hospize.de/docs/hib/Sonder_HIB_02_09.pdf).

THE EPIDEMIOLOGIC AND STATISTICAL PERSPECTIVE

To give a first orientation, let us begin with a few pieces of data concerning the state of end-of-life care in Germany. Every year, about 830,000 people die in Germany. Ca. 60 percent need hospice and palliative care in general, at least 10–15 percent need palliatively oriented care due to progressed chronic illness, as some, e.g. patients with progressed neurological illnesses, do many years before, and others, e.g. with severe heart- and vessel complaints, do for just a few weeks. The German Hospice Foundation is of the opinion that four of five critically ill or dying doesn't receive an adequate care as it is implied by „hospice” in the literal sense as a promise of accompaniment⁶.

It goes without saying that the largest group of palliative patients consists of people who are ill with cancer. Various analyses show that 60–80 percent of cancer patients suffer pain in progressive states of their illness and that 20 percent of cancer patients dying annually need special palliative-medical care to ease their symptoms. It is evident that the quota of these patients will be rising due to demographical development. Thus statistics that show 3 million people over eighty for 2000 will rise to 5.3 million for 2020.

But even judging from today's demand the state of end-of-life care in Germany cannot, at large, be deemed satisfactory. Firstly, this is certainly connected with the delayed start of hospice care and palliative medicine. The first palliative ward set up in Cologne in 1984, the first hospice in 1983. Today there are nearly 158 palliative wards and 163 in-patient hospices and day hospices. Additionally, there are 1.084 ambulatory hospice services that cared for 174.384 dying patients. Although the number of people with critical illnesses who are being cared for by a hospice- or palliative service is constantly on the rise the overall relation is, all considered, disillusioning. Of 830.000 people who die annually 87.5 percent don't receive an accompaniment and care.

The current situation is also reflected in the places people die at. Referring to Cancer patients analysis has determined the following facts in regard to these places: 51 percent deceased in hospitals, 15 percent in a nursing room, 4 percent in a stationary hospice and 30 percent at home. If there were enough ambulatory services, e.g. palliative-care teams, about two thirds of patients could be cared for at home up to their death as far as their palliative-medical and nursing needs are concerned. On the basis of the current data situation one can cautiously approximate that there are currently about seven to eight palliative places per one million inhabitants while the demand is at about thirty; proportioned to this there are cur-

⁶ Cf. G. Graf, G. Hoever et al., *Hospiz als Versprechen. Zur ethischen Grundlegung der Hospizidee*, Wuppertal 2006; J. Giordano, P.J. Hutchinson, *The „Promise” of Pain Medicine: Profession, Oaths, and the Probity of Practice*, „Pract. Pain Management” 7,8 (2007), p. 78–80.

rently about eleven hospice places per one million inhabitants while the demand is about twenty. The approximated need is thus at 50 palliative and hospice places per one million inhabitants.

This approximation of demand does not *eo ipso* agree with the perspective of hospital operators and insurance companies.

THE PERSPECTIVE OF HOSPITAL OPERATORS AND INSURANCE COMPANIES

Patients who receive end-of-life care or palliative care do not appear to be cheap patients from the perspective of hospital operators and insurance companies. The problem does not chiefly consist of the definition of these patients and of the necessity to provide them with appropriate care, but consists mostly of the inability to calculate the cost of palliative-medical treatment and care as it, still judging from today's standards, presents itself.

These patients are especially cost intensive from the viewpoint of hospital operators, with a high expense of both staff and medical resources. It is, after all, a fact that 20–30 percent of health costs accrue in the last year of life. *Prima facie* it does not seem to be worthwhile from the viewpoint of the hospitals to care for palliative patients. In Germany this is also reflected by the fact that in-patient care is mostly restricted to confessional, church-sponsored hospitals. Furthermore the development and expansion of palliative care networks for in-patient care and the adjustment to the needs of the critically ill and the dying are not as such facilitated by the introduction of DRG systems⁷. The unmodified introduction of diagnosis-related groups (DRGs) for hospital financing will be a major threat to the creation of new and management of existing palliative care units, because DRGs are not designed to reflect the financial needs of palliative care services. The DRG version in operation since 1st January 2003 fails to provide accurate reflection of palliative treatment of the critically ill and the dying. The reason for this may be that the Australian DRG system was the model for the German health care funding system, and in Australia palliative care is not included in DRGs, but funded through other sources⁸. If palliative care units are to remain places of high quality care for the critically ill and the dying and the places of vocational training and further education in the future, special provisions for adequate funding of palliative inpatient hospital treatment must be found.

⁷ Cf. H. Ewald, *Stationäre Palliativmedizin. Finanzierung und Qualitätskriterien unter DRG-Bedingungen* (3. Petersberger Gesundheitssymposium „Palliativmedizin: Herausforderung für das Gesundheitssystem“, 01. Juli 2004).

⁸ Cf. *Analyse der Abbildung palliativmedizinisch behandelter Fälle im australischen AR DR System, Version 4.1. Analyse an Fällen aus dem Jahr 2001, im Auftrag der Deutschen Gesellschaft für Palliativmedizin erstellt durch die DRG Research-Group, Universitätsklinikum Münster, Juli 2002.*

This is why the German Society for Palliative Medicine called for an introduction of a basic DRG „Palliative Complex Care” this year, which, after a transition period, becomes effective in 2007⁹. The problem which has emerged now consists of the fact that palliative medical patients can be subsumed in one group as they share both comparable medical and psychological problems (e.g. critical clinical symptoms, mostly without causal options of treatment, like pain, shortness of breath, distinctive psychological burden, social problems which are hard to solve, spiritual life-crisis) and the similar methods of treatment resulting from those. A different, more heterogeneous picture does, however, present itself when the focus shifts to difference in primary illnesses (all sorts of cancer illnesses, neurological sufferings or those concerning the inner organs, as well as other primary illnesses), and to the wide multitude of individual problems related to the respective main diagnosis and the different duration of stays in the G-DRG-system; referring the duration of stay compare the differences between a pre-final situation, a quickly progressing cancer-related illness: duration of stay from about 31–41 days with four main diagnosis, to a neurological illness in its latest stages, e.g. amyotrophic lateral sclerosis: duration of stay from 19–27 days with five partly overlapping main diagnosis. To be able to deal with the complex pathologies of these patients, a complex, multiprofessional treatment and the close teamwork of the professions involved (specialised doctors and carers, social workers, physiotherapists, psychologists, ministers and others) becomes necessary. Due to this situation, it is impossible to break the palliative treatment down to single groups of diagnosis or to combinations of measures taken. It is, in contrast, constituted by a continual, complex service which has to be rendered by a multi-professional, closely knit team on a daily basis. It is thus impossible or at least very difficult to categorise palliative patients in a homogeneous cost group in the current DRG system. These problems, as they present themselves in Germany, perhaps could lead to the assumption by the insurance companies that end-of-life care in general is, exactly because of its high complexity, ultimately impossible to finance.

It is, of course, true that patients in the last stages of a cancer-related illness are frequently administered with inappropriate and expensive treatment in the last phase of their lives. But of 142 billion Euro spent by Compulsory Insurances in 2002 only 0.071–0.1 billion Euro were spent on palliative and hospice care – which is less than 0.1 percent of the entire spending of the Compulsory Insurances, while the entire expenses for oncology can be assessed at about 50 billion Euro. Seen from that perspective, end-of-life care, including palliative medicine, is still a neglected part of health care. Palliative care comparable to British standards in extent could be ensured with 0.6 billion Euro (0.5 percent of expenses).

⁹ Cf. Deutsche Gesellschaft für Palliativmedizin (DGP). *DRG-InEK-Eingabe* (30.03.04); DGP. *Aktuelle Information zum Thema „Palliativmedizin im DRG-System”* (09.02.2004), in: <http://www.dgpalliativmedizin.de>; cf. the new OPS-982 „Palliativmedizinische Komplexbehandlung” in the OPS-Catalogue of DIMDI 2005.

The financing of hospice work is a small step in this direction: it is established in paragraph 39 a of the SGB (Social Civil Code) V – the German law regulating reimbursement payments by insurance companies – for Stationary and Ambulatory Hospices¹⁰. Patients with an insurance who do not need hospital treatment are still able to claim assistance for inpatient or partial inpatient care in hospices that offer palliative treatment due to the statutes in insurance company contracts. The patient's own share of the total cost is ruled by the graveness of their illness, expressed in a „care level” assessed by the state. Social services provide the patient's share in individual cases. Ten percent of costs still have to be raised by the hospice itself, e.g. by donations. Since 2002 ambulant hospital care has also been sponsored¹¹. Up until that point in time it was exclusively dependent on donations. Seen from that point of view, there are certainly efforts and concepts by insurance companies to establish more complex structures of care, which should, among other equally important factors, ensure the quality, which is, after all, vital to end-of-life care, in a both sustainable and economically sound way. 2004 the revised GKV (Compulsory Insurance) law has come into existence, which includes the concept of so-called integrated care, 2007 the Specialized Ambulatory Palliative Care (§ 37 b SGB V). It enables insurance companies to complete contracts about care that defies the boundaries between different health sectors, or which ensure an interdisciplinary care. A starting subsidiary to the amount of one percent of the takings has been allocated for the years 2004–2006, until now the workability of these concepts will still have to prove itself in reality. The approach, however, of supporting interdisciplinary and multi-professional teamwork, and to abolish the strict separation between inpatient and ambulant care, which still seems to be typical of Germany, seems to point in the right direction as far as end-of-life care is concerned. End-of-life care in its structural development can thus be seen as a paradigm for the qualitative advance of the health care system in general, as a kind of lens which could help us to remember the concrete human being, especially the terminally ill and dying human being in the face of the unavoidable fluctuations in the health care systems. It is, after all, the unredeemable singularity of the dying human being and their last steps in life that does not only stand against sweeping, diagnosis-centred categorisations, but is also in need of a highly complex structure of care, which has to be based on the singular needs, wishes and decisions of the

¹⁰ Cf. *Information des Deutschen Hospiz- und Palliativverbandes über die vom Deutschen Bundestag am 18.06.2009 beschlossene Neuordnung der Finanzierung der ambulanten und stationären Hospizarbeit gemäß § 39 a Abs. 1 und 2 SGB V Stationäre und ambulante Hospizleistungen und § 37 d SGB V Spezialisierte ambulante Palliativversorgung*. Stand 29.06.2009, in: http://www.hospiz.net/stamhole/pdf/stat-amb_p39a-sgb5_info.pdf.

¹¹ Cf. *Bundesarbeitsgemeinschaft Hospiz, Rahmenvereinbarung nach § 39 a Abs. 2 Satz 6 SGB V zu den Voraussetzungen der Förderung sowie zu Inhalt, Qualität und Umfang der ambulanten Hospizarbeit* (03.09.2002).

patient. In short a strategy of rapprochement is necessary to reconcile these tensions as a means to bring stakeholders together in the best interests of the patient¹² as well as to incorporate „an ethical ‘infrastructure and function’ that engages ethical systems and approaches in ways that support and sustain the good to be provided on individual and public levels”¹³.

THE SOCIAL-POLITICAL AND MEDICAL ETHICAL PERSPECTIVE

End-of-life care patients, as well as palliative patients, have been a target group for demographic research and health care measures, but also for limitations of resources in recent years. People do get older, but they are also increasingly sick, so that the alleviation of suffering and the improvement of life quality gain a higher importance than the ability to prolong life by medical-technical means. The question of assisted suicide and care for the dying has been frequently raised in the public discussion of humane dying, with a special focus on ethical and juridical-political problems. Palliative medicine and hospice care are being discussed as an alternative to demands of euthanasia in Germany.

In contrast to the legal prohibition of euthanasia – directly killing by euthanasia is a crime – the physician-assisted suicide, insofar as it results of a free, explicitly articulated will of a patient, is not penalized, because the free, voluntary suicide is not penalized in general. But physician assistance is not in accordance with the medical code in Germany in these cases. On the other side the development of the judiciary in the last years did emphasize the living will of a patient and the power of the guardian or attorney, much more so than before. Following this the Federal medical association did modify their guidelines for the physician-assisted end-of-life care¹⁴. The artificial nutrition (PEG) for instance will now be seen as a medical treatment, which needs not only an indication, but also the informed consent of the patient or his advocate; respectively the treatment has to be finished, when it is opposed by a patient’s testament (living will). It’s not allowed for the physician to ignore a living will by referring to a patient’s presumably implicit will. Since there are great uncertainties about the binding character of the living will in the concrete situation, both on the part of the physicians and on the part of the

¹² Cf. J. Giordano, M.E. Schatman, G. Hoever, *Ethical Insights to Rapprochement in Pain Care: Bringing Stakeholders Together in the Best Interest(s) of the Patient*, „Pain Physician” 12 (2009), p. 803–813.

¹³ J. Giordano, M.E. Scharman, *An Ethical Analysis of Crisis in Chronic Pain Care: Facts, Issues and Problems in Pain Medicine*, part 1, „Pain Physician” 11 (2008), p. 488; cf. M.V. Boswell, J. Giordano, *Evidence-Based or Evidence-Biased: the Need to Re-appraise and Re-align Levels of Information with Stakeholder Values*, „Pain Physician” 12 (2009), p. 283–286.

¹⁴ Cf. Grundsätze der Bundesärztekammer zur ärztlichen Sterbebegleitung, „Deutsches Ärzteblatt” 101,19 (2004), 7. Mai 2004, A. 1298–1299.

patients or their families¹⁵, the German Bundestag changed this year the legislation concerning the Living will and the examination by the Court of Protection (Civil Code, volume 4, section 3, title 2: § 1901 a and § 1904 so that the limitation to irreversible underlying disorders which, in spite of medical treatment, will lead to death is rejected, and the examination by the Court of Protection should not take place in every case but only in the event of disagreement between the legal representative and the doctor¹⁶.

In Germany – it seems to me – there exists the danger that dying and death will alter more and more to become a thing of administration. The hospice and palliative medicine movement did start with the intention, to free dying and death of a false institutionalization in the sense of segmentization and putting under taboo in modern societies. It can't be denied that dying and death in Germany could undergo a process of a new institutionalization. Because of this the palliative patient could be made an autonomous subject of law in a highly abstractive manner, without sufficiently reflecting on his specific rights and needs – as it is articulated e.g. in a recommendation of the Parliamentary Assembly of the Council of Europe in 1999¹⁷.

In Germany the debate on dying and death surely is very strong determined by an attitude of avoidance, that is of euthanasia and the physician assisted suicide. But the consequence of this focus is that the question of appropriate medical decision making at the end of life – for instance in the case of withdrawing or withholding of therapies – is extremely underrepresented. The issue does already start with the fact that, in a medical perspective, the palliative patient has to be defined by the approach of treatment or by structural symptoms e.g. intractable physical distress etc. But in both cases it is not always easy even for the physicians to define, and often there don't exist definite limits. This request in the single, specific case a way of treatment, which is not only based on evidence, but also has a cognitive orientation, that means the willingness to outline the plan of care together with the patient and his relatives, to communicate the aims of the treatment and to bear a common shared responsibility¹⁸.

¹⁵ Cf. German Bundestag (15th electoral term). Study Commission Ethics and Law in Modern Medicine, *Interim report on living wills* (Printed Paper 15/3700; 13.09.2004), in: www.bundestag.de/parlament/kommissionen/ethik_med/index.html.

¹⁶ Cf. German Bundestag (16th electorate term), *Entwurf eines Dritten Gesetzes zur Änderung des Betreuungsrechts* (Printed paper 16/8442), 18. Juni 2009; Bundesrat, *Drittes Gesetz zur Änderung des betreuungsrechts* (Printed paper 593/09), 19.06.09.

¹⁷ Cf. Council of Europe, *Protection of the human rights and dignity of the terminally ill and the dying*, Parliamentary Assembly Recommendation 1418 (1999).

¹⁸ Cf. J. Giordano, *The Moral Community of the Clinical Pain Medicine Encounter*, „Pract. Pain Management“ 6,5 (2006), p. 60–63; C. Müller-Busch, *Freiheit zum Tod und Grenzen ärztlicher Hilfe beim Sterben – Palliativmedizin im Spannungsfeld zwischen Lebens- und Sterbehilfe*, Dortmund 2001; C. Müller-Busch, *Zur Behandlung von ethischen Problemen und Konflikten in der Palliativmedizin*,

Both the interpretation for instance of a dying parent's will as well as the withdrawing or withholding of treatment in patients who are unable to decide for themselves should not merely be guided by the debate on active and passive physician-assisted help to dying, but should rather take into account the appropriateness or inappropriateness of medical actions in the specific situation. And although intensive care and palliative care have different aims and priorities, there are common problems of decision making which could benefit from a shared orientation and interdisciplinary debate. By taking into account the question of appropriateness or inappropriateness of medical actions in the specific situation of end-of-life care intensive care and palliative care could rather be seen as a mutual supplement than as a contradiction. Perhaps the debate on patient's autonomy and self-determination could be developed to a debate on dialogue and human relations, on shared social commitment and responsibility. Therefore I think that in Germany we need a renewed discussion about the use of knowledge and intellectual virtues in hospice and palliative care in order to a virtue-based foundation of moral agency¹⁹.

LASTLY A SHORT REFLECTION ON THE PALLIATIVE PATIENT

Who is the palliative patient in the view of the affected persons. It seems to be important to see him not only as a victim of his disease. Of course the medical indication of treatment is, in the first place, given by the fact that life and quality of life are reduced through intractable symptoms and distress, but it is also important to see that the palliative patient does not only has fears, but also hopes, and that reflecting on existential problems will not only challenge himself, but also his relatives. „The end of life can foster a realization of finitude that may instigate patients' need to subjectively reflect upon the life lived, maximize familial relationships and social contact, and generate a sense of existential closure”²⁰. The death of the man is not simply an end. Because we are born as human beings who are endowed with freedom, dignity, unalienable rights, we have to reflect what it means that freedom transcends all conditions on the one hand, but is the freedom of a being

„Zeitschrift für Palliativmedizin” 3 (2002), p. 70–76. C. Müller-Busch, *Intensivmedizin – Palliativmedizin. Widerspruch oder Ergänzung? Gedanken zu ethischen Fragen und Prinzipien sterbenskranker Menschen*, „Anästhesiologie Intensivmedizin Notfallmedizin Schmerztherapie” 36 (2001), p. 725–734.

¹⁹ Cf. J. Giordano, *On Knowing. The use of knowledge and intellectual virtues in Practical Pain Management*, „Pract. Pain Management” 6,3 (2006), p. 65–67; J. Giordano, *Moral Agency in Pain Medicine: Philosophy, Practice and Virtue*, „Pain Physician” 9 (2006), p. 41–46; Y. Maricich, J. Giordano, *Pain, Suffering, and the Ethics of Pain Medicine: Is a Deontic Foundation sufficient?*, „The American Journal of Preventive Medicine” 17 (2007), p. 44–52.

²⁰ J. Giordano, *Hospice, Palliative Care, and Pain Medicine: Meeting the Obligations of Non-Abandonment and Preserving the Personal Dignity of Terminally Ill Patients*, „Del Med Jrl” 78,11 (2006), p. 419–422, 419; cf. J. Giordano, *Chronic Pain and Spiritual Implications and practical applications for chronic pain management*, „Pract. Pain Management” 7,3 (2007), p. 64–68.

which is mortal on the other. Whatever quality of life may be, its definite profile will be given and attained by dying and death²¹.

Surely this may seem like a paradox or a mystery that dying and death could be experienced not only as something that happens to us in a completely passive way, but as something that could also be called completion.

Everyone will have to find the answer to these questions in freedom, but it is also commonly true that we have to learn to die – to philosophize is learning to die. This request respect, understanding, empathy, truthfulness and close relationship. And so the end-of-life care of a palliative patient until the life disclosure could be experienced by all those who are involved in this process as something that also is an enrichment for the own life.

END-OF-LIFE CARE IN GERMANY

An overview

Summary

The author presents an overview on the issue of care for the terminally ill from the triple perspective: a) epidemiological and statistical perspective, b) the perspective of hospital operators and insurance companies, c) the social-political and medical-ethical perspective. All the perspectives are analysed in details. The author of the paper emphasises that a terminally ill person who receives a palliative care should not be viewed only as a separated victim of the illness. Of course from the medical point of view in such cases life quality is systematically reduced, however a palliative patient does not only have fears and worries, but also hope which embraces his family and the nearest and dearest. The end of life can contribute to realisation of its finitude and looking at death as a sort of fulfilment of life. Experience of life coming to its end by persons involved in palliative care may be not only something passive, but an active enrichment of their own existence.

TROSKA O TERMINALNIE CHORYCH W NIEMCZECH

Ogólny zarys problematyki

Streszczenie

Autor proponuje spojrzenie na zagadnienie troski o terminalnie chorych z potrójnej perspektywy: a) epidemiologicznej i statystycznej, b) zapewnienia opieki medycznej oraz finansowania, c) społeczno-politycznej oraz medyczno-etycznej. Wszystkie perspektywy są szczegółowo przeanalizowane. Autor tekstu podkreśla, że osoba chora terminalnie i otrzymująca pomoc paliatywną nie powinna być postrzegana jedynie jako odosobniona ofiara choroby. Oczywiście z medycznego punktu widzenia jakość życia w takich przypadkach podlega systematycznemu pogorszeniu, jednak człowiek chory nie doświadcza jedynie obaw i strachu, ale także nadziei, która obejmuje również rodzinę i osoby najbliższe

²¹ Cf. G. Hoever, *Der Mensch und sein Tod – zu anthropologischen Grundlagen einer hospizlichen Ethik*, „Die Hospiz-Zeitschrift” 6,4 (2004), p. 4–7.

choremu. Życie zmierzające do swego ziemskiego końca może przyczynić się do uświadomienia sobie skończoności naszego bytu, a także do spojrzenia na śmierć jako swego rodzaju dopełnienie życia. Także dla osób zaangażowanych w pomoc paliatywną może być to nie tylko doświadczenie pasywne, ale aktywne ubogacenie ich własnej egzystencji.

Keywords: Germany, paliative care, paliative medicine, terminal illness, terminal patients

Słowa kluczowe: choroba terminalna, medycyna paliatywna, Niemcy, opieka paliatywna, pacjenci terminalni