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Palliative care: a model for innovative health and social policies

Report
Social, Health and Family Affairs Committee
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Summary

The importance of palliative care as a comprehensive approach, with the potential to complete and improve existing care programmes, is now recognised in many of the Council of Europe's member states. Palliative care is a substantial and socially innovative addition to curative, highly scientific medicine, where subjective well-being of the patient comes after the goal of curing an illness and which involves therapy-related restrictions and sometimes massive side-effects.

The report endeavours to highlight the central problem of the highly sophisticated and costly health care provided particularly in western Europe, which, at ever shorter intervals, produces new medical techniques and medicines, raising high public expectations of curative success. At the same time, however, this type of health care is increasingly – and obviously – failing to meet the basic needs of people suffering from chronic or rare diseases.

The rapporteur considers palliative care as a model for innovative health and social policies. Palliative care does not simply meet a cultural and humanitarian need of the most pressing kind. It also provides an innovative structure which, if intelligently developed, will not only produce sustainable change in the health sector, but may also serve as a recipe for success in other policy areas with serious, systemic and recurrent problems (for example, drug prevention).

The rapporteur therefore regards palliative care as an essential component of appropriate health care based on a humane concept of human dignity, autonomy, human rights, patient rights and a generally acknowledged perception of solidarity and social cohesion.

The report advocates a wide-ranging discussion in society on the priorities of health care based on sensible health objectives and on the fundamental rights of the patients. These objectives must not be left to competition between lobby groups, as the protection of fundamental rights is a government task and not a matter for pressure group politics.

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A. Draft resolution

1. The Parliamentary Assembly notes that palliative care is a substantial and socially innovative addition to curative, highly scientific medicine, where subjective well-being of the patient comes after the goal of curing an illness and which involves therapy-related restrictions and sometimes massive side-effects.

2. In this connection, the Assembly builds its position on the World Heath Organization (WHO) definition: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

3. The Assembly nevertheless underlines that the innovative potential of the approach is not given sufficient emphasis in this definition, which could lead public opinion to believe that palliative care is a humanitarian luxury which we can no longer afford in the current difficult economic situation.

4. The Assembly notes that, especially in the final stages of life and in spite of the high standards and huge costs involved, contemporary medical care fails to meet the basic needs of many people (seriously ill, chronically ill, patients requiring high levels of individual care). Against the background of the increasing domination of health and social policies by economics, growing numbers of people do not have a strong enough lobby to defend their basic rights.

5. The Assembly regards palliative care as a model for innovative health and social policies, as it takes account of the changes in our perceptions of health and illness and does not assume that curing diseases is the precondition for self-determination and participation in society. Autonomy is accordingly the requirement for a subjective form of “health”, which includes people deciding themselves how to deal with illness and death.

6. The Assembly notes that palliative care enables people who have serious illnesses, are suffering pain or are in a state of great despair to exercise self-determination. The approach is not therefore just based on need but contributes directly to human, civic and participation rights being asserted right up to death.

7. The Assembly believes that there is an urgent need to extend the scope of this innovative treatment and care method. In addition to the terminally ill, palliative care should be available to the seriously ill and chronically ill and all those requiring high levels of individual care who may benefit from the approach.

8. Palliative care can be seen as an approach to an appropriate type of care developed on a practical level, which involves patient-oriented integration of medicine and care, as well as the provision of other health-related services and social resources. For instance, this includes the successful involvement of voluntary helpers and the possibility of including social, psychological and spiritual support if necessary. This can be more important for individual patients than medical care in the stricter sense.

9. With the above, the Assembly also draws conclusions from the debate on the subject of euthanasia, which showed that liberal constitutional states cannot leave ethical questions concerning the life and death of individuals unanswered.

10. Sticking to ethical pluralism does not ensure maximum individual freedom in ethical issues but in society it gives randomness, relativism and practical nihilism precedence over properly founded ethical positions. This results in general disorientation and ultimately in the erosion of the liberal constitutional state.

11. In this connection, the Assembly refers to the relevant recommendations on dealing with the terminally ill as set out in the European Health Committee’s report (1980) on “problems related to death: care for the dying” and in its Recommendation 1418 (1999) on protection of the human rights and dignity of the terminally ill and the dying.

12. It recognises that the limits of any medical intervention are determined by the autonomy of the individual patients insofar as they express their will not to receive curative treatment or, regardless of any medical assessment of their state of health, have done so explicitly in a living will, for instance.

13. The Assembly hopes that palliative care also offers individuals who have given up hope the prospect of dying in dignity if they are allowed to turn down curative medicine but accept pain relief and social support.

14. It therefore regards palliative care as an essential component of appropriate health care based on a humane concept of human dignity, autonomy, human rights, civic rights, patient rights and a generally acknowledged perception of solidarity and social cohesion.

15. It underlines that Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care already provides a good basis for strengthening the palliative care approach.

16. The Assembly endorses the four applications of palliative care listed in Recommendation Rec (2003)24 following the WHO definition, namely symptom control; psychological, spiritual and emotional support; support for the family; and bereavement support, and accordingly specifically recommends that member states:

16.1. establish a consistent and comprehensible health-policy approach to palliative care;

16.2. promote international co-operation between the various organisations, institutions, research institutes and other players in the palliative care movement.

17. In view of the great differences in developments in this area in the various countries in Europe, the Assembly is aware that, although rapid implementation in existing health-care structures is desirable with a view to sustainable funding arrangements, the funding arrangements themselves may involve serious obstacles for such a flexible care and treatment approach.

18. It therefore believes there is a need for detailed analysis of structural obstacles and accurate analysis of needs on the basis of a minimum data set of the kind called for in the Appendix to Recommendation Rec(2003)24 in order to achieve sustainable, effective changes in existing health systems.

19. It notes that wide-ranging discussion in society on the priorities of health care based on sensible health objectives is necessary if fundamental rights are to take precedence over further patient rights in the health system. As the protection of fundamental rights is a government task, this must not be left to pressure group politics.

20. The Assembly believes that ethics therefore has a fundamental role to play as a practical philosophy in shaping the discussion of health objectives and care priorities in society.

21. Therefore, with regard to general recommendations, the Assembly recommends that member states:

21.1. focus on ethics not only in application issues but as a matter of principle, as only the clarification and typological classification of fundamental positions will enable a stable consensus to be reached in society about controversial ethical issues and a fair allocation of resources;

21.2. seek to ensure improved rewards for non-product-related services both in health and in economic and financial policies so that social policy can draw on economic-policy and fiscal incentives and do more to counter the increasing domination of society by economics;

21.3. in general, seek to strengthen primary health care so as to protect patients against inappropriate medical intervention and place greater emphasis again on the methodical significance of communication between doctor and patient as the basis for rational, patient-oriented medicine;

21.4. given governments' capacity for influence, promote an approach to medicine in society which highlights palliative care as a key pillar of care provision to which patients are entitled.

22. Moreover, with regard to practical recommendations, the Assembly recommends that member states:

22.1. regard and promote effective symptom control for seriously ill patients as a key requirement for the doctor-patient relationship and patient self-determination, thereby also bringing the innovative potential of the palliative care method into the domain of curative medicine;

22.2. within a consistent health-policy approach for the specific strategy of improving palliative health care provision, identify practical indicators that can be used to check what progress has been made in patient care over a given period;

22.3. draw up annual reports so that shortcomings can be analysed as quickly as possible and dealt with appropriately;

22.4. react promptly, for instance through special arrangements for the funding of palliative care, if it becomes apparent that the appropriate use of painkillers is not taking place as desired or the standardisation of hospital treatment (Diagnosis – related groups –DRGs) is having a negative impact on existing structures and practices;

22.5. with regard to legal regulations on living wills:

22.5.1. avoid creating legal arrangements which could lead to interpretation problems in practice;

22.5.2. conduct a comprehensive assessment of the legal consequences, taking account of possible legal side-effects such as asset liability (“care as a financial loss”).

B. Explanatory memorandum, by Mr Wodarg

1. General considerations

1. The importance of palliative care as a comprehensive, holistic approach, with the potential to complete and improve existing care programmes is now recognised in many of the world's countries.

2. Initially, palliative care was seen as a way of caring for people whose death was imminent. It is now recognised that holistic care offers people with incurable diseases great benefits far earlier than that. For example, it includes and completes curative therapies, whose undesirable side-effects can be mitigated by early intervention, or addresses – with psychosocial or spiritual support – needs which can be more depressing for patients than physical illness. In practical respects, too, limiting palliative care to end-of-life patients is counterproductive, since the idea that they have been "given up on" frightens them and puts them on the defensive.

3. Extending such care to persons who are not life-threateningly ill (for example, chronic sufferers) and to the elderly in general is a major task for the future. The care currently provided for people in these categories is particularly inadequate, reflecting the need to make savings in the health care sector. Like people in the final stage of their lives, chronic sufferers have a multitude of disorders – including psychosocial disorders – and so palliative care's comprehensive approach has much to offer them.

4. The importance attached to patient autonomy, particularly in the last phase of life, reflects the fact that dying is no longer, in many cases, a natural occurrence, but is heavily influenced by medical decisions and usually takes place in medical facilities. Medically prolonged life can be prolonged suffering, and many people may seek to avoid it by demanding active euthanasia or making living wills, in which they specifically forego treatment.

5. Comprehensive, country-wide provision of palliative care programmes is needed to effectively stem the ever more pressing demand for active euthanasia in many European countries.

6. The European Region of the World Health Organization (WHO) comprises 52 states with a total of 879 million inhabitants. In those states, some 9 million people die every year, 24% of them from cancer. Given the increasingly high average age, particularly in western countries, an enormous rise in the number of cancer patients can be expected. It is widely agreed that demographic growth makes the need for country-wide, high-quality palliative care even more urgent.

7. While the European Union's commitment to providing improved palliative care programmes has so far been limited, steadily growing efforts have been made in recent years in a broader European context. The first reliable and systematic data collected by the European Association for Palliative Care (EAPC), which was founded in 1988, show that only a very few states provide no hospice and palliative care.

8. However, country comparisons show major differences in the quality of care, and in the speed with which this sector is developing. In certain states (for example, Germany), the provision of good care is a problem only at regional level. An essential factor in successful development seems to be the extent to which palliative care has been implemented within the existing health care and other parts of the social security system.[1]

9. In recent years, the World Health Organization (WHO) has made an intensive study of issues relating to palliative care, and it published two documents dealing with specific aspects of such care in 2004.[2] Its definition of palliative care (1999, updated in 2002) is internationally accepted: "Palliative care is an approach aimed at improving the quality of life of patients and of their families, who are confronted with problems accompanying a life-threatening disorder, that is, by preventing and easing suffering as well as by early recognition and treatment of pain as well as of other physical, psychosocial and spiritual disorders."[3]

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1. David Clark and Carlos Centeno, "Palliative care in Europe: an emerging approach to comparative analysis", *Clinical Medicine*, Vol. 6, No. 2, March/April 2006, pp. 197-201.

2. World Health Organization (WHO) (2004), *Palliative care – The solid facts*, WHO Publishing, Geneva. World Health Organization (WHO) (2004), *Better palliative care for older people*, WHO Publishing, Geneva.

3. C. Sepulveda, A. Marlin, T. Yoshida and A. Ullrich, "Palliative care: the World Health Organization's global perspective", *Journal of Pain and Symptom Management*, 24, 2002, pp. 91-96. World Health Organization (WHO) (2002), definition of palliative care, http://www.who.int/cancer/palliative/definition/en/print.html Clark and Centeno, op. cit., p. 199, comment as follows on WHO's efforts: "Despite the powerful symbolic language of these endeavours, unfortunately as yet there appears to be little evidence of the impact of such activities." "Palliative care is an approach that improves the quality

10. Unlike the EU, the Council of Europe had already started working intensively on the development of palliative care. Inspired by the European Health Committee's 1980 report, "Problems related to death: care for the dying", and by Parliamentary Assembly Recommendation 1418 (1999) on protection of the human rights and dignity of the terminally ill and the dying, the Committee of Ministers decided, in 2001, to set up an expert committee. Within two years, this committee had drawn up European guidelines on the organisation of palliative medical and nursing care. On 12 November 2003, the Committee of Ministers adopted Recommendation Rec(2003)24 to the member states on the organisation of palliative care, which was buttressed by a comprehensive explanatory document. By the following year, this text had been translated into 17 European languages, and so had clearly been noted by most European countries.[4]

11. The report describes palliative care as "an integral part of the health-care system and an inalienable element of a citizen's right to health care" (recommendation). "Palliative care policies should be based on values propounded by the Council of Europe: human rights and patients' rights, human dignity, social cohesion, democracy, equity, solidarity, equal gender opportunities, participation and freedom of choice."

12. Palliative care has the following core dimensions:

– symptom control;

– psychological, spiritual and emotional support;

– support for families;

– support for the bereaved.

13. The report calls on the governments of the member states to adopt the policies, and the legislative and other measures needed to provide a coherent and comprehensive national policy framework, and to promote international networking between organisations, research institutions and other agencies active in the palliative care field.

14. It notes that "while in many countries the greater part of health-care budgets is spent on people in their final years of life, they do not always receive the care that is most appropriate to their needs".

15. This cautious wording highlights the central problem of the highly sophisticated and costly health care provided particularly in western Europe, which, at ever shorter intervals, produces new medical techniques and medicines, raising high public expectations of curative success. At the same time, however, this type of health care is increasingly – and obviously – failing to meet the basic needs of people suffering from chronic or rare diseases, or from conditions certain to prove fatal in the short or longer term.

16. A comprehensive vision of palliative care as an attempt to rethink the whole concept of medicine emerged, for obvious reasons, in the 1960s from a civic movement which extended beyond the European cultural area. In many countries throughout the world, certain sectors of society are demanding, and providing, patients and sufferers with various forms of complementary care that are meant to compensate for the present shortcomings of "modern medicine".

17. This development is the fruit of parallel efforts by private individuals and professionals. In some countries (for example, the United Kingdom), it has achieved remarkable successes within a relatively short time, in spite of very limited public funding.

18. Since the first palliative care programmes started in the United Kingdom, approaches to implementing them have changed in many ways. Specialised centres or hospices are still the commonest providing institutions, but care units are increasingly being established in acute patient centres, oncological centres and university hospitals. In addition to the hospital units and home teams that provide palliative care, many countries have set up mobile or support teams in general hospitals to supervise care and treatment of patients. There are programmes in nursing homes, and also highly specialised teams, which bring hospital facilities to patients' homes. Day care centres are another possibility. Lately, palliative care teams have not been confined to set locations; in some countries, they now provide help wherever it is needed – in hospitals, patients' homes or nursing homes.

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of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual."

4. Council of Europe (2003) Recommendation Rec(2003)24 of the Committee of Ministers to the member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003 at the 860th meeting of the Ministers' Deputies.

19. One major requirement for the future is indicators that can be used to determine the effectiveness of the legal framework, and the quality of care, training and research. Devising such indicators is not easy, as the example of one suggested indicator, "place of death", shows.[5]

20. Continuing expansion of structures that are not focused on specific diseases (cancer, Aids) is threatened by the serious financial problems that high unemployment causes for social security systems. At a time when huge sums are being spent annually on stabilising and safeguarding the existence of people who are wholly or partly unable to support themselves and their children unaided, and the number of employed taxpayers is constantly falling, there is little scope for investment in the future (education, training, environment) or in innovative social and health care projects. The extent to which voters will reward MPs for pursuing longer term political strategies is doubtful – particularly if these entail benefit cuts that are instantly felt by the masses.

21. As it is, the level of care in the nursing sector is already inadequate. Impending demographic changes will considerably aggravate this problem, unless existing structures are modified sustainably. Caring for palliative patients in nursing homes will become one of the main problems of the next decade. The palliative care approach will be particularly important in caring for the elderly – as indeed it already is today.

22. Germany is not the only country where the seriously ill and the dying have no lobby. Political and health care decision makers do not see palliative patients as lucrative clients. This is a fundamental problem that needs airing, and politicians must tackle it bravely.

23. Palliative care does not simply meet a cultural and humanitarian need of the most pressing kind. It also provides an innovative structure which, if intelligently developed, will not only produce sustainable change in the health sector, but may also serve as a recipe for success in other policy areas with serious, systemic and recurrent problems (drug prevention, education, labour market).

24. Considerable attention must be paid to the concept of autonomy, and to this principle's significance in medical decision making. Playing a really major role in palliative care, patient orientation is one important indicator of success. Even if the data are hard to collect, we need to know whether patients feel more autonomous as a result of palliative care, and what significance they attach to this increase in their capacity to act (for example, decide where they want to die). At the present stage of the debate, patient autonomy is an issue only in relation to medically indicated treatment, for example, when patients refuse it (they cannot demand procedures that are not medically indicated). Problems are caused by the various factors that may affect the medical indication. Nor is it quite clear how borderline cases are to be assessed. A patient may want to go home, for example, but relatives refuse to provide care (for example, because they feel unable to cope). How can a doctor evaluate free will in an Alzheimer's patient, who may not understand his explanations fully?

25. Europe is a prolific source of best practices: next, we shall look at provisional data from studies carried out by a task force set up by the European Association of Palliative Care. These studies set out to evaluate the development of palliative care in Europe. They are jointly produced by several organisations, including Hospice Information, the International Association for Hospice and Palliative Care, and the International Observatory on End-of-Life Care at the University of Lancaster.

26. The data reveal wide differences in the provision of palliative care between countries, regions in the same country (for example, urban and rural areas), a one-sided emphasis on certain patient groups (cancer patients), inadequate provision for children in comparison with adults, and insufficient involvement of the care sector. Few countries have official treatment standards, and even fewer have standards laid down by governments.[6]

27. Few people would deny that death is still a taboo subject for scientists and the public. In medicine, this becomes patent when it turns out that doctors, whose training has given them a vast amount of specialised knowledge, still have no idea how to deal with dying people in practice. Against this background, the successes scored by that new speciality, palliative medicine, are indeed highly gratifying – but a systematic, scientific look at the past remains essential. We should, after all, be anxious to find out how such a vital field for medical skill could simply be ignored.

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5. S.W. Tolle, A.G. Rosenfeld, V.P. Tilden and Y. Park, "Oregon's low in-hospital death rates: what determines where people die and satisfaction with decisions on place of death?", *Ann Intern Med*, 130, 1999, pp. 681-5.
6. See overview under: www.hospices.com/standards/.

2. The problem: a fatal automatism

28. The increasing demand for active euthanasia in the interest of patient autonomy is another reason why intensive scientific discussion of the various conceptions of autonomy is needed. Far from bolstering autonomy, living wills may actually generate a dangerous illusion of autonomy, tempting doctors to decide against patients' vital interests in genuinely borderline situations, and damaging the bond of trust between doctors and patients.[7]

29. The introduction of living wills, which is now being discussed in Germany, offers no solution to the problem of properly ascertaining patients' wishes, since those wishes give doctors an adequate basis for decision making only when they are unequivocally expressed. In practice, they are usually embodied in contradictory statements, which require clarification or, when this is impossible, skilful interpretation, to give doctors clear guidance. Indeed, few living wills are contradiction free.

30. There is a question which, in terms of the doctor's human duty to care for despairing patients, is beyond discussion, but is vital from an ethical standpoint – the specific purpose of ethical codes. Should they, for example, help doctors to take difficult decisions of conscience on care of the dying by relaxing ethical standards (guidelines)? Surely, this very relaxing of standards makes for confusion in the longer term, since ethics – as a rational yardstick for action and a pointer to options within definite, clearly defined limits – gets lost along the way?

31. The genuine ethical importance of successful communication between doctor and patient does not lie in the latter's being able, with the former's help, to make an (ideally) informed choice between possible therapeutic options, like a supermarket customer deciding to buy a certain product. It lies in the patient's assuming responsibility for this decision, and being clearly aware of the drawbacks and side-effects of a therapeutic measure before he/she decides.

32. Questions that affect the life or death of human beings cannot be left undecided in a liberal legal system. On the other hand, deciding not to decide them, and leaving them open to a range of answers or the random preferences of individuals, is in itself a momentous decision against reason as counsellor. Rational discussion holds the only key to reducing the many problems and solutions at issue to basics. Indeed, it offers the only way of gaining an overall picture of the alternatives available, steering clear of imagined consensus or specious disagreement, and averting the danger of the debate's becoming ideological.

2.1. Utilitarianism: bliss without sense

33. For a long time, it was blithely assumed that the health benefits of medical treatment could be objectively and scientifically proved with sufficient clarity, but the structural shortcomings of objective methods are now becoming more apparent. Clinical tests can reliably demonstrate the utility of medicines or treatment only if: *a*. the physical causes on which the latter are based are genuinely present, and *b*. any alternative treatments or absence of treatment are systematically compared with the new one. Clinical tests for the approval of medicines are far less strictly regulated than they ought to be. They require subsequent evaluation, of the kind carried out for evidence-based medicine by independent scientists.[8]

34. Care should also be studied, broadening the focus to take in the everyday conditions in which medicines, for example, are used. Benefits for specific patients should be considered as well. The hope is that new methods can be used to keep the wildly proliferating medical possibilities under rational control. Pharmaceutical firms have no interest in critical research of this kind. Willingness to invest additional funds in the evaluation of clinical tests and in research on care depends on public awareness of the difficult issue of quality of medical treatment, which obviously needs to be guaranteed, in everyday medical practice, by quality management as well. The concept of quality has been called the "sleeping giant" of rational health care,[9] and the ethical dimension now confronts science with a serious problem of method.

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7. Interim report of the Committee of Enquiry on Ethics and Law in Modern Medicine, 15th electoral term, "'Living wills', conclusions and recommendations", Document 15/3700.

8. Norbert Schmacke, *Wie viel Medizin verträgt der Mensch*, 2nd edition, Bonn/Bad Homburg, 2005. See in particular the two chapters: "Qualitätsdebatte in der Medizin, das ungenutzte Kapital im Gesundheitswesen" and "Evidenzbasierte Medizin und individuelle Therapieziele", pp. 79-126.

9. D.M. Berwick, "Health services research and quality of care assignment for the 1990s", *Med Care*, 27, 1989, pp. 763-771.

35. The whole debate on quality, which has been given a new dimension by the concept – also very important for palliative care – of the patient's quality of life, reflects the not immediately obvious fact that knowledge with a secure and objective clinical basis can be totally irrelevant to human health. What yardstick to apply, if objectivity itself is not enough, is, however, a question we cannot answer definitely at present. In addition to that of effectiveness, the concept of appropriateness provides extra bearings that can help us to determine utility. In the present discussion, the use of several yardsticks makes it harder to reach a clear verdict. Theoretical method assessment, of the kind possible when ethical aims are the yardstick, could prove extremely useful in the quality debate.

36. One genuinely ethical issue in health policy is the fair allocation of resources. Without a sensible vision of health goals and care priorities, public debate – which is also needed to secure consensus – is likely to get bogged down in the battle of conflicting interests and lobby groups.[10] Patient autonomy is a very important concept for health policy in general and palliative care in particular. Comparison of utilitarian and other social theories, ethical theories that are purely political and ethical theories that are based on personal ethics, may be very helpful in trying to form a first, general idea of its significance. There is no room for the autonomous individual in purely political ethics, and even less in pure social theory.

37. Theories that see the state or society as substantial entities tend to see social processes as automatic, as things that need to be put on the right track, but can then be left to regulate themselves. In these theories, there can be no irreconcilable conflict between the interests and rights of individuals and those of the community as a whole. In a modern, variant-like system theory, things are always seen from the standpoint of the existing system, which is why – given the acute signs of crisis in social insurance systems – new mechanisms and levers are desperately being sought to repair the automatic process. The system is to become capable of learning, and subsystems are to limit themselves and take on responsibilities.

38. Concepts, which are actually meaningful only when applied to individuals, are thus being applied to systems. In the past, many people were unwilling to speak of ethics in a social context, and certainly not of personal ethics. Almost as a matter of course, people today regard ethics as unnecessary for life in the community, since social theory supplies an automatism that works, and so makes ethics a purely private matter. In many contexts, and particularly in discussion of old age, care and dying, ethics has now been rediscovered in the social context too, and some of the things that were said in the past have a very uncomfortable ring.[11]

2.2. Systemic problems: economy as an end in itself

39. It is becoming apparent that end and means have already been extensively reversed in the care sector. Instead of the institution's serving the people it caters for, those people are shoring up the institution, and have to adjust to things which – in terms of the institution – are seen as making economic sense. Money is being spent, not on carers, but on products and computer software.[12]

40. In general, this insistence on economic aspects encourages the health system to pursue the wrong goals. It is re-visualised as another "growth market" or "job machine", and alienated from its real purpose, that of serving the sick. The growing tendency to see society in economic terms generates fatal patterns of dependence, and makes fear of losing one's job the mainspring of human action. An ideologically coloured economy, of the kind analysed in connection with utilitarian theory, creates psychologically unbearable working conditions, makes people sick or sicker (more in need of care) than they need to be, and – as justifying social theory – stifles dissent.

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10. On my initiative, the Committee of Enquiry on Ethics and Law in Modern Medicine set up a separate subject group on allocation: completed ahead of time because of the holding of early elections in 2005, the report devotes a separate chapter to this issue. Enquete-Kommission Ethik und Recht der modernen Medizin, "Über den Stand der Arbeit", Bt-Drs. 15/5980, pp. 13-47.

11. Verena Wetzstein, "Alzheimer-Demenz – Entstehung eines Krankheitsbegriffs", in *Tagungsdokumentation: Altersdemenz und Morbus Alzheimer, Jahrestagung des Nationalen Ethikrates 2005*, pp. 37-48. Thomas Klie, "Altersdemenz als Herausforderung für die Gesellschaft", ibid., pp. 65-81.

12. For this reason, an initiative launched by the University of Bielefeld and the Heime Research Co., and led by the psychiatrist Professor Klaus Dörner, called in 2001 for the setting-up of a committee of enquiry on "homes" to make the public more aware of the plight of people in institutions. Unfortunately, the proposal for establishment of this body, which I tabled, did not get the necessary support in parliament.

41. "Economisation" is often seen as a lack of willingness to tackle questions of cost rationally, and rejected on that basis. Here, we use the term to mean that economic considerations take precedence when political goals are being determined. It is precisely this approach that marks the difference between a liberal market position, which attaches equal importance to economic and other goals, and a neo-liberal position, which focuses on trade issues.[13]

42. Discussion frequently ignores the fact that serious ethical conflicts arise in practice – certainly with considerable effects on health – when financial and competitive pressures make service providers give customers bad advice, for example, omit to mention the drawbacks of certain products or services, to ensure their own economic survival. The problem here is payment on results for counselling. The negative effects of bad advice often reach the customer a long way down the line, sometimes giving rise to immense secondary costs, which the community has to cover, if important questions have previously been left to the individual's discretion.

43. Looking at the present state of nursing care in Germany, it has to be said that the funding of palliative medical services within the existing health sector structures is a key problem that has yet to be solved. Palliative care requires a high-person/low-technology approach, which explains why voluntary work is so important in many European countries.

44. In Germany, strict demarcation of the various sectors and trades causes serious interface problems. Increased competition between service providers for the limited resources available, encouraged in recent years by politicians for economic reasons, has forced statutory health insurance bodies to compete more than before for young, well-paid members. As a result of badly planned fiscal equalisation, which fails to take account of the real risks of disease and costs caused by sick members – and although certain services (including palliative care under the present reform law) must be provided – these bodies are noticeably reluctant to provide services for the chronically or terminally ill, for fear of attracting the (economically) "wrong" customers.

45. In many health care systems worldwide, there is a growing impression that the structural changes introduced to cut costs (diagnosed-related groups – DRGs) are not suited to palliative care. Important advances made in that highly specialised sector are now under threat, since multimorbid patients with multiple health-related, psychological and social problems cannot be standardised.[14]

46. The economic sums that have been done for the health system are wrong – not just morally or in terms of health policy, but economically too. As a result, the wrong market incentives are themselves becoming a health problem, one which neither the health system, the welfare state, nor the labour market can solve. The market, whose laws we obey, wants tradable products. These are the only ones suited to the world market, and national governments have, in their neo-liberal eagerness, made the fatal mistake of overlooking the change in economic policy that the product/service relationship has brought about.

47. Products are edging services out, and being deployed in the belief that the latter, which cost far more, will somehow be dragged along behind – and be covered by their profit margins. With product-pricing competition becoming ever more aggressive, this is now a total illusion. As a result, services – by comparison with products – are underpriced. Doctors receive a pittance for making house calls and looking after their patients in a human spirit, and are forced to make up the economic shortfall by prescribing various products.

48. The extent to which the welfare state can make up for this mistaken economic policy is limited – particularly since transnational firms notoriously externalise social costs and reap stock exchange benefits from mass redundancies. The result of globalisation is, at most, increased prosperity for a few people in the short term. And it is no longer true, as we can see ever more clearly, that everyone benefits indirectly via a welfare state, which functions effectively and assuages social conflicts. The profits go to a few, who become ever fewer, and systematically evade their social responsibilities. The longer term result for everyone is, however, environmental and social dumping, armed and unarmed conflict over resources, and the problem of mass unemployment, which the world trade system makes insoluble, even in the rich industrial nations.

49. Consistent and effective sustainability programmes, capable of counteracting the "dictatorship of the short term" imposed by the economic system, will thus be vital to survival in the medium term. To work later, however, they must be implemented now. In political terms, this means that the increasingly serious constraints and consequences of globalisation (increasing competitive pressure, unemployment, declining tax

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13. Jerry Mander and Edward Goldsmith (eds.), *The case against the global economy*, London, 2001.
14. N. Roeder, E. Klaschik, M. Cremer, G. Lindena and C. Juhra, "DRGs in Palliativmedizin – ist die palliativmedizinische Begleitung Schwerkranker pauschalierbar?"*, Das Krankenhaus*, 2002, pp. 1000-1004.

revenue, poor working conditions, energy waste, and severe environmental damage) must be tackled in the short term, and new, trendsetting structures established. This challenge can be met only by promoting policies that generate new synergies in various fields.

50. Personal ethics should be used to put the welfare state and medicine on a new tack (this is possible, in model form, in the sphere of palliative care), and can supply a consistent and practical concept of autonomy. This concept, as we have seen, is complex, and it can – if its abstract, guiding function is properly grasped – both assist legislators and contribute to the meaningful life-planning and personal development of individuals, who must themselves be strong and independent to support a strong community and functioning state system.

3. Bases for change

3.1. Medicine's essential task: to serve the whole person

51. A conception of illness that is still largely based on scientific paradigms cannot allow adequately for its social dimension – a dimension which is clearly present, for example, in most mental illnesses and in psychosomatic diseases, which are still not easily delimited. The effects produced by changes in a person's way of life, old age and environmental factors, which underlie chronic illnesses or multimorbidity, are also beyond the reach of clear diagnosis and causal therapy.

52. Radical changes in the range of illnesses in the 20th and 21st centuries, demographic trends that make geriatric medicine and care important, a new self-awareness among patients and, last but not least, the pressure exerted by powerful expectations that medicine itself has partly generated together constitute a major challenge. An idea familiar for many years, which has only recently resurfaced in public consciousness, is that of the link between health prospects and poverty. Looking back in the field of primary prevention, many things, regrettably, were not done; looking ahead, we have no viable plan for the future.[15]

53. Given the extent of the problems, medicine will not be the only, or probably even the most important, strategy. At all events, doctors will also have to realise that resources currently tied up in curative medicine are needed in other areas with strong relevance to health, for example, education, social assistance and environment – and act accordingly. Growth in the health sector is by no means a good thing for the community, if it makes no difference which areas are growing. Blind confidence in the market – the belief that only the economy matters, that growth anywhere is good – is no guarantee of progress, and the fact that doctors and pharmaceutical firms are working hand in hand is no indication of health service quality.

54. The problem for patients is not usually dying as such, but fear of pain. The problem for families is their inability to form a true picture of the situation. They do not want to assume that a relative is dying, since this may not be correct. The same uncertainty affects doctors, whose training has not prepared them adequately for cases where there is no hope. The situation is a bad one, when doctors are unable to show patients and their families the path that leads beyond fear, uncertainty and ignorance. And yet, there is no doubt who the guide should normally be.

55. The general practitioner's guiding function – now, after a period during which general medicine was massively neglected in favour of specialised medicine, which health systems saw as a way of avoiding double consultations and saving money – is totally obvious in the case of dying patients and their needs. General practitioners (GPs) can protect patients against pain, fear and, above all, pointless medical intervention, and ensure that they really receive the attention they require. Admittedly, this depends on their efforts' being recognised and properly remunerated, which is not the case at present.

56. The fact that the training given doctors and nursing staff does not teach them how to deal with people who can no longer be cured throws an unflattering light on the medical profession's perception of itself, and on the society that helped to shape that perception, or may in the past have wanted it. We shall thus explore the impact of perceptions of illness and signs of change in that area.[16]

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15. Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen, *Kooperation und Verantwortung, Voraussetzungen einer zielorientierten Gesundheitsversorgung*, Opinion 2007, abridged, had a separate chapter on this topic, pp. 83-101.

16. Johannes Bircher and Karl-H. Wehkamp, *Das ungenutzte Potential der Medizin, Analyse von Gesundheit und Krankheit zu Beginn des 21. Jahrhunderts*, Zurich, 2006, pp. 35-77. The following references on conceptions of health and sickness are taken from it.

57. This again raises the question of the fairness of the social system in which we live, and its presumed conception of autonomy has massive effects on the community and the state, which must ensure autonomy and participation of everyone, and not just the children of rich parents who, having been massively sponsored from the start, have been able to secure the few lucrative jobs the system offers, and who also – of course – do best out of an economically determined health system.

58. When illness is seen in a certain light, dying itself can be a creative process. At the end, people who have given up on life may succeed in doing something which, in their prime, they had increasingly failed to do: form new relationships or put old ones on a new footing. To that extent, the extreme situation of dying can even, in a higher sense, be qualitatively better than a life paralysed by meaningless routine.

3.2. Health systems: patient-focused goal-setting

59. It is very important to explain the basis of palliative care and make people see what autonomy means and how it functions as patient autonomy. Only when we cast off certain prejudices will we be willing to renounce resources that we think beneficial to ourselves, in favour of those who really need them. The aim of rational debate is insight. Unless many people have it, democracy ceases to work.

60. Unlike evidence-based medicine, which concentrates on evaluating the findings of clinical research, research on care has to consider questions of appropriateness. Clinical research wants, for example, absolute proof that a medicine works, but research on care looks at its effects in everyday conditions. Often, clinical research systematically ignores relevant everyday factors, or uses too few test subjects to establish the presence of side-effects that appear when more people take a medicine. The expert committee itself acknowledges that the concept of appropriateness has not so far been appropriately “put to work” in practice.

61. There is another factor with a vital bearing on palliative care: it is a well-known fact that cost-benefit-quality calculations are inadequately backed by evaluated research findings, and they systematically leave out a factor that is, in practice, an important quality indicator: the time available for each patient. When economic sums are being done, time is factored in, with other variables, as one of the things that determine effectiveness. Time is money. The most time-saving means and methods are the ones that get used. In care models that give patients the right to decide where they want to be accommodated, time is uniquely important. There are thus very good reasons for doubting that combining the various parameters gives a good picture of the complex requirements of health care.

62. Care as a whole should aim to ensure, using minimum resources, that patients are able to help themselves and, as far as possible, lead normal lives. This rational rationing of medical treatment is not primarily dictated by cost pressures on the system, but by the desire to spare patients’ medically motivated interventions and chain-reaction treatment, which can even prove fatal in extreme cases, but usually make them permanently dependent on further treatment. If good primary care made sure that patients saw specialists only when this was medically necessary, everyone would have equal access to them.

63. Taking the concept of autonomy as a basis and using the above goals as a yardstick, the reform debate could be redirected. Since both doctors and patients need to be more aware of quality and cost, an important part of this would be reviving the cost debate as a second element, for the purpose of allowing that awareness to develop and influence their conduct. No additional checks and monetary incentives are needed when autonomy underlies the process, which is not self-sustaining, but requires action from both sides. False economic incentives would be eliminated first, and not second as at present, for the purpose of again making personal rationality – systemically misdirected to start with – rational in terms of the system, under pressure of costs.

64. Doctor-patient communication must be seen, and remunerated, as an important first step in medical treatment. Care must therefore be taken to ensure that it is not, in practice, a ritual dispatched with minimum delay, as a prelude to the “real thing”, ideally based on scientific findings and aimed at objective effectiveness. Patients badly need independent counselling, particularly when their complaints resist clear organic classification, and they have – perhaps – been wandering for some time within the system. It is true that self-help has generated some innovative structures in this area, but the extra information available to patients on the Internet is not necessarily good for the doctor-patient relationship.

65. No patient can want maximum medical care. But every patient rightly wants maximum carefulness, and here there are serious problems, partly owing to lack of time resulting from economic pressure. What we have here is a vicious circle, and we need to break out of it, instead of looking for ever new ways of controlling it.

General practitioners/family doctors could play a major part in defusing numerous problems that are a source of conflicting interests and huge difficulties for patients within the health system. In this way, they would stop being gatekeepers, and become health-keepers.

66. Their practice could cover four important fields of action:

– independent health counselling on possible causes of illness and treatment options, based on empirical quality research and including information on specialists (out-patient/in-patient), funding bodies, help available when public health insurers will not pay, changing insurers, supplementary insurers, care options;

– primary prevention, since GPs are probably the first service providers in the system to spot problems, for example, drug dependence;

– co-ordination of more complex forms of treatment or of care required (GPs as case managers).

– medical activity in individual or group practices, for example, in connection with palliative care.

4. Palliative care: co-operation based on responsibility

4.1. The concept of care in palliative care: rational goals

67. Before looking more closely at particularly important aspects of care, some basic definitions, and types of palliative care.[17]

68. Home care generally means that patients are looked after at home. As used in German, however, the term can also denote certain forms of care provided at home for, for example, cancer patients, and also food and blood transfusion programmes organised by firms for home-care patients.

69. Hospice: the term is derived from the Latin *hospitum*, meaning shelter, but also hospitality. The concept dates back to the early stages in the spread of Christianity in the Roman Empire, when hospices provided accommodation and assistance for travellers, the poor, the sick and the dying. In the 4th century, the institution spread beyond the eastern Mediterranean under the leadership of monastic orders, who looked after pilgrims. It was first applied solely to the provision of care and comfort for the dying by Jeanne Garnier, who founded the first hospice in Lyons in 1842, followed by others in France. Hospices were also founded in other countries, sometimes a great deal later: Ireland in 1879, the United States in 1899, England in 1905. Cicely Saunders, who opened St Christoper's Hospice in London in 1967, is regarded as the founder of the modern hospice movement. In Germany, the first residential hospice was not founded until 1986, in Aachen, although the country has had a hospice movement since the 1960s.[18] In addition to the practical task of looking after the terminally ill and dying, another, and equally important, aim of the movement is to involve the public in health care, and promote humane and helpful attitudes to dying.

70. Hospice work, hospice care: the four internationally recognised criteria for hospice work are: hospice facilities are intended both for the dying and their families; holistic support is provided by a multiprofessional team; team members have special symptom-control skills; and round-the-clock care is provided, nights and weekends included.

71. Out-patient hospice schemes, various hospice and palliative services: these look after the dying at home and cover a very wide range of activities. Their primary task is to educate and inform, and provide psychosocial support for the dying and their families with the help of trained volunteers. Out-patient services, which also have professional staff, can take on additional or specialised counselling, nursing or medical tasks, and – depending on the extent of their professional training – provide ongoing home care, which helps to make hospitalisation unnecessary – even in complicated cases.

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17. The information given here is based on the interim report of the Committee of Enquiry on Ethics and Law in Modern Medicine, "Improving care of the seriously ill and dying in Germany via palliative medicine and hospice services", Document 15/5858 of 22/06/2005, and on the report (appendix) on Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care.

18. In social history terms, this development ties in with the general civil rights movement in the 1960s, one of whose demands, in the United States and Great Britain, was for more consultation and solidarity in welfare and health systems. See Enquete-Kommission Demographischer Wandel, *Herausforderungen unserer älter werdenden Gesellschaft an den Einzelnen und die Politik* (zur Sache 3/2002), Berlin, 2002, p. 588.

72. In-patient hospice: an institution that lies outside the normal intensive care circuit, is independently housed, funded and organised, and has its own staff and approach. Smaller, family-type hospices take, on average, 16 terminally ill patients, whose deaths are imminent, who cannot be looked after at home, and who do not require treatment in a hospital or palliative unit. They are thus seen as complementing out-patient services and can, in principle, provide longer term care. The atmosphere is deliberately non-hospital, rooms are bright, and overnight accommodation and tea-making facilities are available for families. The main emphasis is on pain relief, symptom control, palliative nursing care, and psychosocial and spiritual support. This is why staff should be specially trained and why, in many countries, funding by public health insurance bodies is required. Medical care can be provided by general practitioners or via co-operation with pain treatment centres or doctors specialising in palliative medicine.

73. Day hospice/children's hospice: many in-patient hospices have day-care facilities, to relieve pressure on families or provide medical services for people who basically want to be cared for at home, but children's hospices are separate institutions, which are equipped to meet the special needs of seriously ill children, and also specialise in supporting siblings. Length of care is one of the things that distinguish them from adult facilities, since this starts when the illness is diagnosed. In the case of seriously ill children, care may extend over several years. This can cause serious financial problems, in cases where public health insurance schemes refund only minimum amounts. The data analysed so far suggest that, in most countries, care provision for seriously ill children is very much in deficit.

74. Multiprofessional team: terminally ill people can have physical, psychological, social and spiritual problems, which are often mutually aggravating. Comprehensive care should thus be able to rely on the expertise of various professional groups. In palliative medicine, these include specialised doctors and nurses, as well as voluntary workers and colleagues from other healing and outside professions, for example, social workers, physiotherapists, psychologists, clergy, etc.

75. Palliative care: the internationally accepted term, as defined by WHO in 2002, for a holistic, multiprofessional approach "aimed at improving the quality of life of patients and of their families, who are confronted with problems accompanying a life-threatening disorder, that is, by preventing and easing suffering as well as by early recognition and treatment of pain as well as of other physical, psychosocial and spiritual disorders".

76. Palliative medicine: derived from the Latin *pallium*, cloak or protection. The first "Hospital Support Team" was set up at St Louis Hospital, New York, in 1974. The world's first palliative unit was opened at the Royal Victoria Hospital in Montreal (Canada) in 1975, and its founder, Belfour Mount, was the first user of the term "palliative". Palliative medicine is the active, holistic treatment of patients with incurable, progressive and advanced illnesses, whose life expectation is limited. It seeks to relieve physical suffering, and also psychological, social and spiritual problems. Its main aim is improved quality of life for patients and also their families, who receive continued support after the patient has died. In German, "palliative medicine" also covers the English "palliative care", and thus includes medical, nursing and psychosocial care. In the strict sense, however, palliative medicine is the essential contribution made by medical specialists to palliative care.

77. Palliative therapy: by contrast, this strictly denotes treatment that is intended to prolong life or improve quality of life, even when curative effects can no longer be expected. In oncology, it includes, for example, such cancer-specific forms of treatment as chemotherapy, radiation therapy, hormone therapy and surgery. In medical practice, palliative therapy and palliative medicine are not mutually exclusive, and neither is support therapy, which is designed to mitigate the side-effects of necessary treatment and minimise the unpleasant effects of, for example, chemotherapy.

78. Palliative nursing: denotes the specialised nursing skills and practices deployed in palliative care. Qualified voluntary assistants are a vital part of the caring team, but benefit greatly from being led by a specially trained head nurse. Their main tasks are to: monitor pain relief and symptom control; take palliative nursing measures, for example, change complicated dressings, operate pump systems, etc.; direct and advise families on medical/nursing activities; provide psychosocial support for patients and their families; help them to cope with sickness and the process of dying; support the bereaved; and advise on welfare law and help as required.

79. Palliative unit: a department in a hospital/nursing home that specialises in treatment, care and support for palliative patients with particularly complex symptoms and ailments. A characteristic feature is again the presence of a multidisciplinary team, possibly comprising – in addition to highly specialised medical, nursing and also psychosocial staff – voluntary hospice assistants. Depending on the patient's needs, priority in these units may go to medical, nursing, psychosocial or spiritual problems. Great importance is attached to the organisation of co-operation and communication. They are usually independent units, enjoying maximum

autonomy, that is, doctor and nursing staff are solely responsible for their patients. Palliative units should be organised and led by specialised doctors, pledged to inter-disciplinary co-operation. The particularly intensive and personal care given patients not only makes for successful pain relief and symptom control in most cases, but also ensures that patients and their families receive comprehensive support. The aim is to reduce distress caused by sickness and treatment, and – if possible – stabilise the care situation to a point where the patient can leave. Ideally, palliative units are networked with other institutions, units or outpatient doctors, and sometimes play a co-ordinating role in setting up networks. They provide an essential basis for clinical research and for specialised initial and further training.

80. The special methodology of palliative care – the subject-focused approach, which pain therapy and recent research on dying will be used to illustrate – is a function of clear goal-setting, based on close consideration of the patient and his/her environment. Medicine as a whole still urgently requires evaluation of methods chiefly focused on qualitative aspects – aspects that medical research is increasingly acknowledging.[19] Epistemological back-linking of qualitative research, of the kind that graded models of human self-awareness make possible, is something that we shall thus promote systematically here, particularly since illnesses like dementia (and accidents too) provoke regression to rudimentary forms of self-awareness, and since being able to form an accurate picture of their patients' level of self-awareness can be vital for those providing treatment.

81. Pain is subjective. Research on post-operative pain therapy has shown that patients whose pain has the same physical cause (for example, an abdominal incision) need painkillers in hugely varying quantities to achieve satisfactory pain relief.[20] Since there are no objective criteria for measuring intensity of pain, assessment is based on the patient's description and on the effects of pain-relief measures taken earlier or just started by the doctor. Numerical and visual analogy scales can be helpful in recording and documenting subjective pain intensity. Patients enter their pain on a scale running from 0 (no pain) to 10 (worst pain imaginable).

82. At present, we have only indications and estimates concerning, for example, frequency of cancer pain. However, these reflect enormous variations. At the early stage of the illness, some 20% to 50% of patients report pain, at the advanced stage 60% to 95%.[21] Using present techniques, 90% could be treated successfully, but in practice this often does not happen, either because the expertise is lacking or because the pain's intensity is underestimated, and so-called weak opioids[22] are prescribed. Prejudice against painkillers still has strong determining effects, and pain treatment is time-consuming, since constant monitoring and communication are needed to get the dose right. Morphine-type medicines are also relatively expensive.

83. There are various pharmacological ways of influencing pain, depending on where it originates: intestinal pain must be treated differently from pain directly or indirectly caused by factors irritating or otherwise affecting the nerve paths or central nervous system. Diagnosis of the illness is not enough to determine the type of pain. This is one of the reasons why specialisation is important, and indeed necessary.

84. Also responsible for failure to diagnose pain correctly are prejudices – still widespread even among doctors – concerning the effect of powerful painkillers. International experience of cancer pain treatment indicates that morphine-type medicines, if properly used, will not turn patients into addicts or make them resistant in ways that will necessitate constant increasing of the dose. Nor do they accelerate the dying process. Everyone knows that painkillers are not the only medicines that may do harm if the dose is incorrect. When used, however, they must be constantly monitored and adjusted by the doctor until the patient dies. An IAPC task force recently published a list of 33 medicines for 23 different symptoms, which provides a very useful basis for further discussion.[23]

85. It is true that Germany is one of the countries where morphine is increasingly prescribed, but we must assume that care provision for patients in pain is still extremely inadequate. Consumption rose from 0.8 kilograms per million inhabitants in 1985 to 17.7 kilograms per million inhabitants in 2002 – but the estimated

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19. The appendix to Rec. 24 No. 138 refers to the shortage of data on methods, and notes the growing interest in qualitative research. No. 119-143 as a whole on quality improvement and research.
20. K.A. Lehmann, *Der postoperative Schmerz*, Berlin, 1994.
21. K.M. Foley, "Pain assessment and cancer pain syndromes", in D. Doyle, G.W. Hanks and N. MacDonald (eds.), *Oxford textbook of palliative medicine*, Oxford 1998, pp. 310 ff.
22. In Germany, the so-called strong opioids are prescription-only for analgesic use. They include: morphine, Hydromorphon, Fentanyl, Buprenorphin, Oxycodon and Levomethadon. Tramadol and Tilidin are among those not covered by the Analgesics Decree.
23. L. De Lima, "The International Association for Hospice and Palliative Care list of essential medicines for palliative care", *Palliat Med*, 20, 2006, pp. 647-51.

need is 80 kilograms per million inhabitants.[24] Partly owing to powerful prejudice, real progress can be expected only when the community sends a clear signal in this area, and when painkillers for patients with chronically painful conditions are not funded like other medicines, for example, from budgets, as in Germany. Doctors may still be insufficiently informed, and there is a danger that reversal of the trend may be called for.

86. Even medicinal freedom from suffering is not a universal goal. Coping with pain from early childhood on may itself be part of a person's self-image or an upbringing based on endurance, not avoidance. Levels of tolerance are deducible from this sociology of pain, which we need to ascertain individual perceptions.

87. A decisive figure for the theory of hospice care (and not just in Germany) is the American-Swiss doctor, Elisabeth Kübler-Ross, who did pioneering research on dying. With students of theology, she interviewed dying patients and formulated a five-stage model, which must be carefully interpreted when applied in specific cases. The five stages she distinguishes are: 1. denial; 2. anger; 3. bargaining; 4. depression; and 5. acceptance.

88. Hope remains at these stages, but its focus shifts: from hoping for a miracle, for discovery of a new treatment, to hoping for a pain-free death. The central point is her vision of dying as a process, which takes a different course with each patient. In accompanying the dying, her model is extremely useful, since it makes the human emotions involved comprehensible. Helpers should not attempt, however, to accelerate the dying person's progress towards the final phase. They are simply there to offer support. The real work must be done by the patient.[25]

89. Critics who complain that the five-stage model takes insufficient account of individual peculiarities are missing its methodological significance. Idealisation takes individual cases and distils from them an abstract generalisation, which must then be re-individualised when applied in practice.[26] In their design and use, models like this do not require a basis in exhaustive empirical data to be generally applicable. Admittedly, there is one thing the subject-focused approach cannot do: let others, for example, professional service providers, do the subject's work for him/her.

90. Subject-focused research does not aim at comfort medicine. It requires exceptional communication skills, which users can acquire only by practising the art of self-scrutiny, for example, by reflecting on their own values. They cannot really help others to negotiate complex subjective processes if they themselves start from a reductive world view.

91. To start with, the significance of communication and its theoretical foundations was ignored in the basic training provided for palliative carers. Today, it is on every curriculum. This is definitely not a skill that is automatically acquired on the job, or constitutes an "optional extra". Indeed, most of the problems in palliative care are due, not to medical/nursing mistakes, but to poor communication. Communication skills are a necessary and important part of all health care, and this should ideally be allowed for in palliative carers' basic training. This is why the team approach works better, and why it quickly won acceptance in particularly hectic areas of everyday clinical practice, for example, intensive care.

92. Sensible goal-setting is palliative medicine's starting point: length is no adequate indicator of a human life's quality, since the time gained by treatment may, under treatment conditions, be a time of futile suffering. Psychologically, it resembles time spent sitting in the death-cell, where the prisoner has no idea whether, and when, the execution will actually take place. Using a purely quantitative yardstick, length of life may involve a total loss of quality and become grossly inhuman – leaving the patient indefinitely suspended between hope and fear. Being treated for something that cannot be cured is purgatory on earth. Rescue is unlikely, and suffering is certain, but probably futile, and stops the patient from finding inner peace – or spiritual "salvation" in the broadest sense of the term.

93. Deliberately refusing further curative treatment rewards the patient with living time that he/she can shape meaningfully. Autonomy brings new scope for action. When symptoms are effectively controlled, the seriously ill can focus on things that have real meaning for them. Only when these new possibilities are constructively used, does quality of life become a reality for them and for their families. This is why, even in palliative care, quality of life is a doubtful concept. It is not the service provider, professional or not, who

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24. International Narcotics Control Board (2002), *Consumption of principal narcotic drugs. Estimated world requirements for 2002, statistics for 2000*, United Nations, New York. E. Klaschik, "Entwicklung und Stand der Palliativmedizin", in S. Husebö and E. Klaschik (eds.), *Palliativmedizin*, Heidelberg 2003.
25. Elisabeth Kübler-Ross, *On death and dying*, 1969. On criticisms of Kübler-Ross, see interim report of the Committee of Enquiry on Ethics and Law in Modern Medicine, p. 10.
26. Description of the idealisation and realisation method in K. Düsing, *Fundamente der Ethik*, pp. 301 ff.

guarantees success, but the patient alone. The initial benefit – a new dimension of meaning, in and through medicine itself – is threatened if quality is ranked above professional requirements, only to be filled once again with quantitative calculations.

94. Obviously, universal provision can be quantified, and standards of medical practice are a yardstick for quality of care. If symptoms cannot be effectively controlled, the necessary scope for action is not there. As we have shown, however, being taken care of is not an end in itself; the autonomous subject is the end in itself, and seeking help is the precondition of the real aim: successful incorporation of dying within one's own life-plan. Accompanying the dying is helping them to live.

95. The distinction between palliative medicine and palliative or curative therapy is thus very important, but we must not conclude that one excludes the other. On the contrary, the patient benefits greatly if the palliative approach is adopted from diagnosis on, as it usually is in children's hospices. Medicine's ability to limit itself is the source of a potential that takes it far beyond the boundaries of a specialised discipline. In practice, patients themselves set the course, and it is only when they stop looking hopefully to therapy that new meanings can emerge and acquire significance for them.

96. The practical aims of care should be based on setting sensible goals to start with – otherwise, ends and means will again be surreptitiously reversed by professionalisation/specialisation. Aims defined in merely objective, professional terms are no adequate yardstick for deciding whether the means employed are the right ones.

4.2. Care with indicators: countries compared

97. The great variations in the development of palliative care in individual countries are due to various factors, which must be carefully distinguished to ensure that thorough assessment does not miss its mark. Nearly all possible indicators must be based on a distinction between things said in public discussion and practical measures taken by governments, for example, in the sphere of health policy. A vigorous community-based hospice movement certainly says something about the public's commitment and awareness, but is no indication of the quality of the care actually provided.

98. Swedish policy, for example, was consistently geared to out-patient rather than hospital care from a very early stage, which is why patients and their families take free nursing care at home for granted.[27] Families caring for patients at home are also given financial help with holidays. Voluntary commitment is insignificant in Sweden and all the Scandinavian countries, but this does not mean that care is generally seen as a matter for experts. Similarly, Spain traditionally attaches great importance to family care, while hospices have a very negative image as places where people are packed off to die.

99. On the government side, various strategies can be identified: some, like those of Sweden, the Netherlands and Belgium, may be aiming at rapid implementation within the existing system: this policy is consistently pursued only when care is as fully integrated as possible, and the means used to promote it are not exclusively focused on specialisation of doctors or hospitals, as the tendency is in France.

100. This strategy covers rapid implementation and possible funding via existing structures, as well as the parallel promotion of palliative care through separate budgets, as in Belgium. It must be distinguished from legislative strategies with no permanent funding base, which may be purely inspirational. This is the situation in Spain, following the government's whirlwind decentralisation of health policy. Care is now good only at regional level, and state involvement has ceased.

101. In Switzerland too, the poor state of care is blamed on sweeping decentralisation. The prevailing attitude among many professionals is described in a report issued by the Société de Médecine et des Soins Palliatifs in 2000 as failure to take the new specialism seriously: "we all know what palliative care is".[28]

102. An important indicator is whether structures are radically adjusted, when this is necessary to fund palliative care in the long term, or whether the changes remain superficial. This is the situation in Germany, where a legal right to out-patient palliative care has at least been entered on the social statute book, but

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27. In a 1979 report, the Swedish Government explicitly rejected the idea of founding special institutions for the dying. C.J. Fürst, "Perspectives on palliative care: Sweden", *Support Cancer Care*, 8, pp. 441-443. Summary of the opinion commissioned by the Committee of Enquiry on Ethics and Law in Modern Medicine on 10 European countries (Austria, Belgium, France, Great Britain, Netherlands, Norway, Poland, Spain, Sweden and Switzerland), p. 59 ff.

28. Appendix, Rec. 24, Nr. 28-31. C. Knipping, "Das Verständnis, die Umsetzung und Qualifizierung von Pallaitive Care in der Schweiz unter besonderer Berücksichtigung der Pflege – eine Literaturrecherche", Master Thesis, St Gallen, 2003.

complex forms of care are still not properly remunerated in practice. A serious problem in Germany is the fact that incentives for integrated care do not apply to all the funding bodies, but start with the service providers, while the funding bodies, for example, health insurance schemes, are expected to compete with one another.

103. These conflicting incentives have a particularly damaging effect on palliative care, even though state subsidies are now being provided, for example, for the co-ordination of existing professional teams. The complexity of mixed funding – by health insurance schemes, care schemes, state subsidies, donations and patients themselves – has stopped it from having any ongoing effect on continued development of care provision.

104. And yet the concept of palliative care is very much in line with the changes needed to bring more co-ordination and responsibility into the German health system, described by the expert council in its current opinion: a new self-image for the various professional groups, easing of the burden on doctors and elimination of a blinkered professional mindset, inclusion of care on an equal footing. However, since consolidation of funding structures and basic reform of care have both been postponed in Germany, it looks as if comprehensive health reform will have to wait until after the next election, in 2009.

105. Even though fewer countries in eastern Europe have in general set out to develop palliative care, there are no signs of an overall difference due to shortage of resources.[29] On the contrary, it is impressive how efficiently a high level of expertise, accompanied by networking, has been achieved in five skill centres (so-called beacons) in Romania, Hungary, Russia (one each) and Poland (two). These centres offer excellent care services, provide training and further training, do research, maintain international contacts and engage in political lobbying. Palliative medicine and hospice work in Poland are regarded as exemplary for eastern Europe.[30]

106. Not the least reason for this is the fact that palliative medicine has been successfully integrated in university courses. Of the 12 medical schools in Poland, 11 offer courses in palliative medicine – optional in three, compulsory in the others – though not always as a separate subject. There are six chairs of palliative medicine, which is not in itself a specialised branch of medicine. However, the extensive further training course – open only to doctors who already have specialised training – had been taken by 55 doctors up to 2004.

107. Germany has adopted the opposite strategy: there are only two chairs, but specialised training is available. Since doctors are poorly paid, there is little demand for further training, although there is, generally, considerable interest among German GPs. Here again, we see that great potential can produce very small results, in spite – or indeed because – of the politicians' energetic efforts to keep costs down.

108. A broad range of further training is also available in Poland. Since 1991, a co-operative scheme, the "British Charity – Polish Hospices Fund", has been playing an important role in the further training of Polish doctors and carers. These can spend time in many British hospices and receive further training there. Their stays are subsidised by the fund. The value of its work for palliative medical care in eastern Europe should not be underestimated. High-level advanced seminars, organised by the Palliative Care Department in Poznan and the WHO Centre for Palliative Care in Oxford, are also on offer in Puszczykowo. The Palliative Care Resource and Training Centre in Poznan runs theoretical and practical courses for medical staff (also from other European countries). Even though funding remains uncertain, it is a further example of effective international co-operation.[31]

109. The main problems reported from eastern Europe make it clear that the situation there is not entirely different from that in the countries of the west: "lack of policy recognition, reimbursement and sustainability; insufficient availability of opioids; recruitment of workforce; lack of medical and nursing equipment; lack of research opportunities; negative cultural stereotypes".[32]

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29. A study by the Eastern and Central European Task Force (ECEPT) shows that there are no basic differences. D. Clark and M. Wright, *Transitions in end of life care. Hospice and related developments in eastern and central Asia*, University of Sheffield, 2002. This study examines 28 countries and uses both quantitative and qualitative methods.

30. F. Nauck, "Hospizarbeit und Palliativmedizin. Europäischer Ausblick", in E. Aulbert, E. Klaschik and D. Kettler (eds.), *Palliativmedizin – Ausdruck gesellschaftlicher Verantwortung*, Stuttgart u.a., p. 3 ff. Specifically on Poland, see also: R. Gronemeyer, M. Fink and M. Globisch, *Studie zur Hospizarbeit in 16 Ländern*, Justus-Liebig University, Giessen, 2004. M. Globisch (2004), "Hungary", i***n*** R. Gronemeyer, M. Fink, M. Globisch and F. Schumann, **Helping people at the end of their lives: hospice and palliative care in Europe**, University of Giessen, Giessen, Germany.

31. The courses are run in co-operation with the Medical Faculty at Karol Marcinkowski University in Poznan, the Polish Association of Palliative Care and the Eastern and Central European Task Force (ECEPT). Another notable feature of the situation in Poland is the fact that, thanks to good further training, palliative paediatric care is already available in 29 regions.

110. Hungary has had a targeted government strategy since 1997. The Health Care Act refers explicitly to palliative care, and establishes a right to symptom control and life with one's family; home care is to be provided when possible, and support for families is also specified. The Hungarian Ministry of Health has published professional guidelines with the Hospice-Palliative Association. The ethical principles, which explicitly raise the question of allocation, are notably strict.[33]

111. Co-operation on palliative care in the interest of patients and their families involves decision makers: patients/families/voluntary workers/professionals/specialists in structures of all kinds: out-patient/in-patient/ comprehensive/networked. Isolated units have major organisational, financial and functional problems, and co-ordination is a job in itself. It has been found, for example, that largely unspecialised services are often unable to judge when outside expertise is needed. Communication becomes far more of a challenge as the number of people involved increases. Structures as complex as this need a long time before they can function really well.

112. Country-wide care provision can basically be taken as a good sign, but is no guarantee per se of sufficient professionalisation or specialisation. Taking another example, care for cancer patients which is good only at regional level, or is merely specialised, is no indication that things overall are moving in the right direction. This is an area where sustainable funding, and ongoing development and expansion, are always desirable.

113. In many respects, Great Britain is, of course, the country with the most highly developed structures and, in many areas, exceptionally well co-ordinated co-operation.[34] But funding is largely based on donations and voluntary commitment. Time will show whether this is sufficient in the long term.

114. The most important indicator of patient autonomy remains place of death, although this – as we have said – is conclusive only when we know where the patient wanted to die, where he/she actually died, and the reasons for this. This kind of data will not be so easily come by. A decline in demand for euthanasia will also be ascertainable only via opinion polls – if the empirical, quantitative approach is adopted. The first, encouraging findings of research on the significance of doctor-patient communication are now available.[35]

115. Country-wide, permanently funded co-operation between service providers with varying degrees of need-tailored specialisation, in the interest of patient autonomy, would be the ideal outcome (for which an indicator is being sought) of health policy efforts. Political efforts aimed at continuous growth and development can be measured by three indicators: Is there a right to palliative care? Is there data-based analysis of needs? Are there a contradiction-free political strategy and official standards?[36]

116. A still more basic question is whether health policy ranks health goals in order of importance, what the order is, and whether it is broadly accepted by the public. Unless the general goal is clearly defined, all the more specific sub-goals will not ultimately survive. On the other hand, a plan based on sensible goals stands a good chance of also being accepted by most members of the public, since "generally binding" means binding on all, not just most. In Germany, it would be an excellent thing if wearing, ideological squabbles between interest groups gave way without delay to ethical debate.

117. Possible indicators of the palliative care movement's vitality in Europe are: the existence of palliative care associations; printed or Web-based directories or monographs listing available palliative care services; articles in scientific journals on the development of palliative care; professionals taking part in palliative care programmes. Other indicators include:

– discussion as to whether implementation in the existing health sector would be a good thing (preconditions of successful integration);

– funding basis (sustainable concepts);

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32. Appendix, Rec. 24, paragraph 16.
33. K. Hegedüs and I.E. Szy, *Palliative care of terminally ill cancer patients*, Hungarian Hospice-Palliative Association, Budapest, 2002.
34. Report of the Committee of Enquiry on Ethics and Law in Modern Medicine, p. 47.
35. M.A. Steward, "Effective physician-patient communication and health outcomes: a review", *Can Med Assoc,* 152, 1995, pp. 1423-1433. Same author, "Evidence on patient-doctor communication", *Cancer Prevention & Control,* 3, 1999, pp. 25-30.
36. Austria, for example, has such official standards: "Gesundheitswesen ÖBf. Abgestufte Hospiz- und Palliativversorgung in Österreich", http://www.gesundheitsministerium.at and so does Scotland: Scottish Home Office HaHD, "Palliaitive cancer guidelines", www.palliativcarescotland.org.

– saturation health care/broad access/flexible structures (for example, cross-sectoral co-operation; phased concept; and general and specialised palliative care);

– patients' interests/quality of life/autonomy (choice of place of care and of death);

– quality of care (access to drugs/quality standards/evaluation or process optimisation/co-operation and communication);

– incorporation in training regulations (multi-step approach; and inclusion of the nursing sector);

– research.

4.3. Quality of care provision: appropriateness of aim and means

118. The specific shortcomings which, in widely varying health systems, have negative effects on the development of complex forms of care like palliative care are:

– the suppression of death and dying in medical training and practice, palliative medicine and communication is not covered in the training given doctors and nursing staff. The subject-oriented approach, which is really needed, has still not won systematic scientific recognition. Communication is accordingly seen as a social skill to be acquired in practice, and not as an approach to treatment and research requiring systematic cultivation, and having major importance outside the individual doctor-patient relationship;

– sectoral division of medical provision and funding, and also a specialisation powerfully encouraged in the past, are responsible for the fact that, in a climate of increasing competition, networking and trans-sectoral, interdisciplinary co-operation in the patient's interest do not come about. Trans-sectoral forms of care provision are undoubtedly badly needed, but are not suitably remunerated in many existing systems. Health policy must accordingly aim at comprehensive integration, which includes funding bodies, and must not be restricted to service providers;

– the funding structures of health care provision are strongly focused on curative and high-tech medicine, with the result that palliative medicine's high person/low technology approach, and adequate psychological, spiritual and emotional support, are insufficiently funded (more is paid for chemotherapy than for palliative care); another economic constraint, which tells against palliative care, is the way in which medicines are budgeted: expensive symptom-control medicines are not used;

– increasing pressure of time, resulting from extra administrative outlay (quality assurance) and economically induced staff shortages, is not seen as a structural problem. Nonetheless, it has direct effects on the quality of the care provided: no time is left for proper communication and human support; there are serious mistakes, for example, in medication which, owing to lack of data can only be corrected later, and so again increase administrative outlay (see the current discussion of patient safety indicators).

119. Basically, three levels of qualification can be distinguished in palliative care (non-specialised basic knowledge; enhanced basic knowledge; specialised knowledge), which should be made compulsory in the training and further training of doctors and carers (care of the sick and the old), and which should in practice (specifically including support for the bereaved) be available country-wide, as required.

120. In practice, it should be assumed that, in addition to institutional facilities of the kind provided by hospitals, nursing homes and hospices, non-specialised palliative care must be generally available, if people are to have a basic right to die at home. For a smaller number of people with more complex symptoms, specialised out-patient teams, either acting simply as advisers, that is, supporting non-specialist colleagues, or themselves providing care, will also be required. For an even smaller number, highly specialised palliative medicine will be needed, for example, within the context of networked palliative units based on hospitals. In addition to dealing directly with unusually complicated cases and acting as co-ordinators, these have the vital task of providing specialised practical training and undertaking research.

121. Possible indicators of an adequate care structure include:

– number of hospice/palliative care beds per million inhabitants (approximately 50 per million in the United Kingdom, which is also the estimated demand in Germany);

– number of out-patient services per million inhabitants (estimated at approximately 4-8 for Nordrhein-Westfalen, while the Act on Safeguarding Competition (Wettbewerbssicherungsgesetz) is based on some 24-32 full-time posts per million inhabitants);

– access to other categories of interdisciplinary and multi-professional counselling for patients and relatives (for example, by psychologists, social workers, pastors, etc.);

– integration of voluntary workers into palliative care on the basis of suitable co-ordination structures (in Germany, posts for out-patient hospice service co-ordinators are funded under Social Code V);

– appropriate funding provision for a country-wide system of out-patient services; funding of co-ordination and networking also planned;

– quality assurance based on, for example, a minimum data set, a standardised documentation system or other measures, such as auditing (as already called for in Committee of Ministers Recommendation Rec(2003)24);

– palliative medicine established as an academic discipline (university chairs, part of the curriculum for medical students);

– palliative medicine as a separate discipline in medicine and nursing (specialised doctors and nurses).

4.4. Team care: professionalisation of society

122. Palliative care's innovative potential will thus require careful analysis in this report. The main reason for this is not the obvious potential it shares with all other specialised professional sectors, but its holistic approach, drawing on knowledge from a wide range of disciplines in the patient's interest, and its working method, which is based not just on inter- and multi-professionalism, but also on tapping other community resources.

123. In palliative medicine, for example, treatment is not based on set objectives, but on goals agreed with the patient. The result is a flexible approach, involving continuous communication with patients and their families, which could serve as a pattern for other types of medical care. Improving the doctor-patient relationship makes the patient more compliant – which may then have significant effects on success of the treatment.

124. The patient is seen as a whole person, and his/her family and social context are also part of the picture. In other words, he/she is not seen as a body or part of a body, and made the object of some necessary therapeutic measure, but remains a subject, embedded in a specific social milieu, which may contribute significantly to care, or itself require help, because of his/her serious illness.

125. Palliative care is based on a complex vision of health and disease. In addition to the possibilities of progress offered by medical technology, which are still foremost in the public mind, and public health issues (healthy workplaces/poverty and health risks), which are worked on using mainly quantitative methods, palliative care introduces a new concept of quality, which also incorporates the patient's subjective perceptions.

126. When dementia, which presents the community with a real challenge, is discussed, the emphasis laid on rational, cognitive skills in connection with autonomy and self-determination is frequently criticised – with the inevitable result that people with dementia are devalued, marginalised and no longer regarded as persons in the full sense. When this happens, no distinction is made between their taking decisions and decisions' being taken for them. Blurring things like this makes it impossible to distinguish the core area of basic rights – the place where autonomous decisions are really taken – from the far broader area of personal rights, which may be age-dependent (like civic rights), or connected with a profession and implying specifically professional rights and obligations.

127. One helpful approach might be to regard autonomy, not as a statistical quantity, but as a potential acquired during life. People need wide-ranging support to cope with the final phase of life. In addition to the step-by-step approach currently followed in improving palliative care structures in various European countries, an effort must be made – in the medium and long term, and if the available services are to be extended to people who are not seriously ill – to develop patients' personal potential and increase their ability to act independently.[37]

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37. Johannes Bircher and Karl-H. Wehkamp, *Das ungenutzte Potential der Medizin, Analyse von Gesundheit und Krankheit zu Beginn des 21. Jahrhunderts*, Zurich, 2006, p. 130. Relevance of the Meikirch model to care provided for seriously ill persons: "This shows that the unavoidable loss of the biologically determined part of potential can – at least to some extent – be compensated for by the personally acquired part of potential, and also by reducing one's expectations of life. There are thus clear indications as to how people can prepare for the final phase of their lives. Repeatedly, one is astonished, and deeply moved, to see how calmly and approvingly some people accept the transition from life to death.

128. Many studies devoted to the problem of dementia and autonomy suggest that more attention should be paid to the need for help and to acceptance of dependence, and less to self-determined rationality, but this misses the real problem, if the necessary distinction with so-called "dysfunctional dependence", which is primarily created (or at least accentuated) by institutional practices, is ignored. As a result, abilities still present are systematically overlooked, and institutional care becomes a threat to dignity, since people are generally seen as requiring more help than they really need or want. This is why the whole problem of age and dignity calls, not for a fresh look at the individual autonomy of people in need of care, but for more self-scrutiny and communication on the part of professionals, who must force the existing system to give them – and those people – more autonomy.

129. Society as a whole has a duty to see that the general conditions of care are such that the team providing it can reflect on what they are doing, communicate and spend time on rehabilitation. "Doctors and carers not infrequently land in situations where they can no longer make specific ethical principles the central basis of their action. … When personal integrity is violated by having to ignore ethical principles, this leads to feelings of guilt, and ultimately profound self-doubt and an inclination to give up the job. This is why it is not just a matter of inculcating ethical principles in training, but also – and above all – of creating working conditions which allow a 'morally acting community' to come into being."[38]

130. A broad range of help is required to preserve autonomy in the last phase of life, when the people concerned need complex assistance. Alongside the present step-by-step approach to improving palliative care structures in various European countries, it will be necessary – if care is extended to people who are not seriously ill – to increase patients' own responsibility and personal potential in the medium or long term.

131. The basic idea in palliative care, that is, that revitalisation and rehabilitation can make a major contribution to the quality of life of people who are seriously ill, can be expanded to include specifically preventive measures, and this involves showing people the direct health benefits that their own efforts may bring. The Latin root, *pallium* (coat), graphically conveys the concept of protection. People must also be protected from themselves. Empowerment, coaching and co-operation motivate more effectively than old-style authoritarianism, compulsory preventive check-ups, the threat of sanctions, or cheap moralising.

132. The report on Committee of Ministers Recommendation Rec(2003)24 rightly emphasises the importance of voluntary helpers, which is often underestimated. Voluntary helpers are not themselves enough, but are necessary for the system to work. They reduce costs by saving specialists' time. Another important aspect is active solidarity (the investment of time instead of money), which strengthens the sense of community and increases personal responsibility.[39]

133. The support given by the working section of the community was an important and even driving force, both in the pioneering phase and for the further development of palliative care. In Germany, the relationship between palliative medicine and the hospice movement had been tense for many years, but intensive efforts on both sides have recently led to improved co-operation. In other countries, too, only a well-balanced system promises success. Co-operation between a professional, semi-professional and private sector is urgently needed in the patients' interest, functions excellently if carefully planned, and must not be regarded as a stopgap dictated by lack of resources. On the contrary, it is the life and soul of the concept.

134. In future, more thought will have to be given to mutual "advantages" for care-recipients and carers, since voluntary work in its present form will soon be phased out. In nearly all countries, voluntary workers are mainly women in their 50s to 70s, who conform to the traditional role model by giving their children and family priority over their own professional development. In nursing care, too, people in this category still bear the brunt without receiving any adequate support or compensation, for example, in respect of still unpaid pension contributions. This structural injustice is, of course, part of the public debate – but hardly any appropriate political action has been taken so far.

Obviously, people like this have been able to develop the personally acquired part of their potential to a point where they can feel positive about the natural process of dying and see as part of life. From the standpoint of social medicine, this raises the question of the measures required to enable as many people as possible to realise this part of their potential sufficiently to cope with the final phase of life and the process of dying."

38. A. Kruse, *Altersdemenz*, Tagungsdokumentation Jahrestagung NER, 2005, p. 53 ff.

39. Klaus Dörner's intelligent criticism of the present health care system starts from the assumption that transferring the task of providing care to anonymous structures and professional institutions is largely responsible for the mainly psychosocial problems that affect recipients and make them develop physical symptoms of disease. Klaus Dörner, *Die Gesundheitsfalle. Woran unsere Medizin krankt. Zwölf Thesen zu ihrer Heilung*, Econ Verlag, Munich, 2003.

135. Statutory unpaid leave for care-providing relatives, of the kind that exists, for example, in Sweden, France and Austria, is highly desirable, but is rarely taken, probably for financial reasons or because those concerned are afraid of losing their jobs, even though dismissal is prohibited.[40] It is already foreseeable that women will no longer be prepared to engage in thankless altruism. The birth-rate figures speak clearly. With a view to guaranteeing care of the old and palliative care in the long term, we also need to consider the risk that other social institutions (for example, churches) may scale down their involvement. Political concepts worked out in the context of voluntary service, civic commitment and demographic change also play a major part in continuing implementation of palliative care, and must be further pursued.

136. In the field of palliative care, participation is not just a label, but a vital element in day-to-day work. In fact, this concept represents the major cultural challenge for liberal societies pampered by prosperity, and it is becoming apparent that being entitled to participate helps us to meet such societal needs as the need to nurse and care for one another. Excessive professionalisation and dependence on public funding are thus risks that the German hospice movement rightly perceives and denounces very clearly.[41]

137. One area to which palliative care might usefully be extended – apart from nursing and caring for the chronically ill – is addiction treatment. A drug policy that is not focused on attacking the root causes, but simply on combating individual addictive substances, will probably only mean robbing Peter to pay Paul. Stress, inability to cope with excessive demands and lack of a role in the community are seminal causes of addiction. Palliative care has paved the way for sensible handling of addictive drugs and can thus contribute established expertise and appropriate practical measures to the treatment of addicts, and to prevention. Former addicts might prove useful partners for co-operation in this field.

138. Approaching this problem rationally thus holds the key to solving it. Prohibition and punishment are the irrational reflexes of impotent lawmakers, and at best provide temporary protection for people who are not yet addicts, although they have started on the path to addiction – and they offer no help against the causes.

139. Harnessing the innovative potential of palliative care as an appropriate approach to treatment and care, while giving basic rights priority over personal rights, depends on the whole community's getting involved, and on making medicine in the narrow sense part of the process. Medicine and nursing care are important co-operation partners, but they cannot act in the community's stead, relying solely on their specialised skills. Care as a professional service cannot be totally funded via insurance, and this approach must in fact be rejected as totally counter-productive, since the "customer" and "claim" mentality of the insured person undermines solidarity in a far more basic sense.

140. Individual freedom and autonomy come from exercising responsibility which is shared with other people. This is why, when the aim is more responsibility and co-operation in the health system, it does not matter whether responsibility is exercised in a professional, voluntary or private capacity. Whatever happens, it is the type of co-operation involved that determines the individual's ability to make his/her contribution in an appropriate manner: autonomy is possible only in the context of shared responsibility for other people. Both in theory and practice, palliative care is thus a matter of shared responsibility and of professional back-up, which is available as and when the individual needs it.

141. When it comes to modernising structures, to make them more flexible and tailor them to individual requirements, Germany is a long way behind. The system's performance will have to be measurable by this very yardstick: quality is the product of time made available by professionals or other people (private individuals/voluntary workers). Quality is not the product of mere cost-benefit efficiency, which involves reckoning time in terms of money – as we have seen, a serious mistake in economic theory, and one that has disastrous effects, not just on the health system, but also on the whole social insurance system. Looking ahead, this forces us to ask: can we afford to go on getting our sums wrong?

4.5. Dementia – The challenge

142. A general pathologisation of old age has, paradoxically, been the result of increased interest in research on Alzheimer's, even though that research has opened the way to sophisticated diagnosis, making it possible to distinguish a "normal", age-related decline in cognitive ability from a typically progressive disease,

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40. The interim report of the Committee of Enquiry on Ethics and Law in Modern Medicine, *Verbesserung der Versorgung Schwerstkranker und Sterbender in Deutschland durch Palliativmedizin und Hospizarbeit,* recommends the introduction of statutory unpaid leave in Germany and outlines the situation in other European countries.

41. The umbrella organisation to which these structures belong – the Bundesarbeitsgemeinschaft Hospiz (BAG Hospiz) – has thus argued that, as part of the present health care reforms, the structures that have developed over time should be expressly mentioned in the law, and taken into account in decision making.

regarded with great alarm by the public. This has a lot to do with the inherent dynamics of science, and with the effects of economic incentives to develop medicines. This is thus an area where, far more than in the case of palliative care and in addition to questions of allocation and the admissibility of active euthanasia, some ethically crucial issues arise: research on patients unable to give their consent, and legal restrictions on genetic diagnosis.

143. In hard figures, this means that approximately 1 million people currently have cognitive impairments that can be ascribed to various forms of dementia. In 2000, there were 12.2 million over-65s in Germany (in 1900, the figure was 3.2 million). It is estimated that the figures for dementia will have doubled by 2030, and that there will be 16.9 million sufferers in 2050. The figures vary with the risk scenarios on which they are based. There is thus nothing really striking in the statement that ageing is the chief risk factor in dementia. This follows logically from the fact that modern medicine, though frequently unable to cure them, can keep the sick alive.

144. In short, it can be said that the real figures do not suggest a frightening scenario, for example, “scourge of the 20th and 21st centuries”, “exploding patient numbers”, “ticking time bomb”. Nonetheless, we obviously need to look ahead and decide how to guarantee care in the future. However high the eventual figures may be, the institutional solution – homes – is unaffordable, and most of those surveyed do not want it.

5. Looking ahead: prospects for a rational Utopia

145. The debate on rationing of care should involve the whole community and not be reduced and confined to the doctor-patient relationship. The fact is, however, that early medicinal treatment of Alzheimer’s is not the only desideratum or option. Care that stimulates and preserves autonomy is time-consuming and thus costly, and should be given priority if, in discussing allocation, we argue from basic rights, which take precedence over more far-reaching (personal) rights. I regard early diagnosis, like the whole debate on genetic diagnosis, as highly problematical in the absence of a preventive strategy or genuine causal therapy.

146. A sensible utopian policy is to make health the focus of co-operative effort, involve as many people and groups as possible, and together pursue the goal of maximum autonomy with and for those who are obliged to live with physical or mental handicaps or incurable diseases. That life goes on until they die, and we should beware of trying to decide, for ourselves or for others, what does or does not constitute a life worth living.

147. Ethics is a theory that is practical in its own terms. The very concept of applied ethics, for example, bioethics, reflects a misunderstanding of its nature. We do not need applied ethics – we need to learn again how to use ethics properly. Ethics are realised in action, not by being used instrumentally to provide justification, soothe consciences, lay claim to exalted values, or serve as a fig-leaf. However, for ethical action or ethically demanding action strategies, such as palliative care, the basic conditions must be right. Making sure that they are is a job for the state.

148. Ethics plays a vital part in the setting of sensible goals, since it ensures, as a philosophical discipline, that the goals are clearly ranked, without being restricted in their content, which can vary greatly between cases. Culturally, the same is true of different peoples: there are various laws, traditions, etc. Setting goals formally is the only way of making them generally binding. Not all goals whose content can be determined, and which may even command majority support, are sensible. The true yardstick of a goal’s general validity is not majority acceptance, but reason. That is why ethics is vital for politics, even though decisions in democracies are taken – for pragmatic reasons – by the majority.

149. Science, on the other hand, wants its research findings to be objective. Scientific objectivity also attempts to satisfy the criterion of general validity, but is usually prevented from doing so by the empirical nature of its procedure, since the necessary data are lacking. Here again, ethics and epistemology can make a very useful contribution – provided that the sciences think more about the methods they employ, and seek real co-operation with other disciplines, for the purpose of acquiring new knowledge.

150. Alzheimer’s research clearly shows that a mechanistic conception[42] of causality does no justice to the complex processes within the human body – quite apart from the fact that reductionism can give no adequate account of the whole human being, in his/her physical, mental and spiritual dimensions. An organism is not a mechanism. Its “functioning” is based on self-organisation and can be explained only by assuming that all

42. For an illustrative example, see C. Haass, p. 23.

natural processes are purposive. Human genetics suffers as a whole from being seen in simplified, mechanistic terms – which makes it self-limiting. An arrogant faith in one's own methods is no guarantee of progress, even when interested groups make huge sums of money available for research.

151. Political philosophers often quote Kant's observation that even a race of demons could establish a state system based on rational legal principles, if they had enough sense. Perhaps we are on the way to becoming such a race of demons with – alas – too little sense. But perhaps we may achieve a new sense of humanity's influence on action, and see that the law can now develop in one of two directions – either eroding the basis it provides, as the current ranking of personal over human rights is doing, or evolving rationally. We will get targeted evolutionary development only if we rely on the ethical principles that gave rise to our law-governed state, instead of dismissing them as poetic hyperbole – as happen in discussion of Article 1, paragraph 1, of the German Constitution, which makes human dignity the supreme legal principle.[43]

152. The automatism we introduced in the name of supposed objectivity and economic laws, relying on the non-self-fulfilling prophecy of the greatest possible happiness of the greatest possible number, is no longer functioning as it was meant to. And it is not making many people rich and happy – on the contrary, it may well be making many people poor and sick, and finally robbing them of dignity too. Indeed, human dignity is an endangered commodity: without citizens who have a liberating vision of society, who stand up for that vision and make it a reality through active, collective commitment, that mutual respect, which is the basis of freely taken decisions and of dignity, will be lost. Autonomy is not automatism.

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Reference to committee: Doc. 10775 and Reference No. 3206 of 17 March 2006.

Draft resolution adopted by the committee on 15 September 2008.

Members of the committee: Mrs Christine McCafferty (Chairperson), Mr Denis Jacquat (1st Vice-Chairperson) (alternate: Mr Yves **Pozzo di Borgo**), Mrs Minodora Cliveti (2nd Vice-Chairperson), Mrs Darinka **Stantcheva** (3rd Vice-Chairperson), Mrs María del Rosario Fátima Aburto Baselga, Mr Francis Agius, Mr Konstantinos Aivaliotis, Mr Farkhad Akhmedov, Mr Vicenç Alay Ferrer, Mrs Sirpa Asko-Seljavaara, Mr Jorodd Asphjell, Mr Lokman **Ayva**, Mr Zigmantas Balčytis, Mr Miguel Barceló Pérez, Mr Andris Berzinš, Mr Roland Blum, Mrs Olena **Bondarenko**, Mrs Monika Brüning, Mrs Bożenna Bukiewicz, Mrs Karmela Caparin, Mr José Carracao Gutiérrez, Mr Igor **Chernyshenko**, Mr Imre Czinege, Mr Karl Donabauer, Mrs Daniela Filipiová, Mr Ilija Filipović, Mr André Flahaut, Mr Paul Flynn, Mrs Pernille Frahm, Mrs Doris Frommelt, Mr Renato Galeazzi, Mr Henk van Gerven, Mrs Sophia Giannaka, Mr Stepan Glăvan, Mr Marcel **Glesener**, Mr Luc Goutry, Mrs Claude Greff, Mr Michael Hancock, Mrs Olha **Herasym'yuk**, Mr Ali Huseynov, Mr Fazail İbrahimli, Mrs Evguenia Jivkova, Mrs Marietta Karamanli, Mr András Kelemen, Mr Peter Kelly, Baroness Knight of Collingtree, Mr Haluk **Koç**, Mr Andrija Mandić, Mr Michal Marcinkiewicz, Mr Bernard **Marquet**, Mr Ruzhdi Matoshi, Mrs Liliane Maury Pasquier, Mr Donato Mosella, Mr Felix Müri, Mrs Maia Nadiradzé, Mrs Carina Ohlsson, Mr Peter Omtzigt, Mrs Lajla Pernaska, Mrs Marietta de Pourbaix-Lundin, Mr Cezar Florin Preda (alternate: Mr Laurentiu **Mironescu**), Mrs Vjerica Radeta, Mr Walter Riester, Mr Andrea Rigoni, Mr Ricardo **Rodrigues**, Mrs Maria de Belém **Roseira**, Mr Alessandro **Rossi**, Mrs Marlene Rupprecht (alternate: Mr Wolfgang **Wodarg**), Mr Indrek Saar, Mr Fidias Sarikas, Mr Andreas Schieder, Mr Ellert B. Schram Mr Gianpaolo Silvestri, Mrs Anna Sobecka, Mrs Michaela Šojdrová, Mr Oleg Ţulea, Mr Alexander Ulrich, Mr Mustafa Ünal, Mr Milan Urbáni, Mrs Nataša Vučković, Mr Dimitry Vyatkin (alternate: Mrs Tatiana **Volozhinskaya**), Mr Victor Yanukovych (alternate: Mr Ivan **Popescu)**, Mrs Barbara Žgajner-Tavš, Mr Vladimir **Zhidkikh**, Ms Naira Zohrabyan.

NB: The names of those members present at the meeting are printed in bold.

Secretariat of the committee: Mr Mezei, Mrs Meunier

43. Wolfgang Wodarg, "Diesseits des Rubikon? Politische Standortbestimmung im Streit um die rechtliche und moralische Auslegung der Menschenwürde", in Matthias Kettner (ed.), *Biomedizin und Menschenwürde*, Frankfurt, 2004, pp. 15-41.