Abstracts

Physician-Assisted Suicide and Health Care Mary Jean Etten

V. P. Tilden, S. W. Tolle, M. A. Lee and C. A. Nelson. 1996. Oregon's physician-assisted suicide vote: its effect on palliative care. *Nursing Outlook* 44, 80–83.

One of the most critical and talked about issues in health care around the world is physician-assisted suicide. In the State of Oregon, USA, in November 1994, voters approved a ballot by a 51 per cent margin to legalize physician-assisted suicide. A temporary court injunction resulted from a legal challenge which was ruled unconstitutional nine months later. Other legal challenges currently have the initiative in the 9th Circuit Court of Appeals. The vote, as narrow as it was, may be viewed as a 'wake-up' call to health-care professionals concerning the status of care for dying patients. The voters' support of the measure may have resulted from their distrust of health-care professionals' understanding of and ability to provide comfort and dignity at the end of life.

The Oregon *Death with Dignity Act* requires the patient to be: (1) in the last six months of life and a resident of Oregon, (2) mentally competent, and (3) the individual must be able to give him or herself the medication. The physician who is the primary care provider must obtain a second opinion from another physician to determine if the person is competent, and determine the prognosis and if the patient suffers from treatable depression. The physician must also: (1) review alternatives with the person, (2) recommend that the person involve the family in making the decision, (3) inform the person that the request may be withdrawn at any time, and (4) instruct the person concerning the expected outcomes of taking the prescribed medications. The person's request for the lethal prescription must be made in writing and verbally over 15 days. Participating physicians must document their adherence to the guidelines; by which they are protected from criminal and civil liabilities. If the law is complied with, death benefits must be paid to the person.

Regardless of the continuing heated debate over the measure, proponents and opponents are generally agreed about certain issues surrounding care at the end-of-life. These include: (1) the ethical and legal right of competent adults who are dying to refuse life-sustaining treatments; (2) the ethical and legal support for health-care givers to withhold or withdraw treatment not helpful to the person but which merely prolongs dying when requested by the family; (3) the need for greater commitment to palliative care and more effective pain management; and (4) defending ethically the use of high doses

of narcotics for pain control even if they unintentionally result in shortening the person's life. Major areas of disagreement focus on interventions for the person that would shorten his or her life.

The American Nurses Association (ANA) and the American Medical Association (AMA) oppose physician-assisted suicide (PAS). The position of the ANA not only forbids assisted suicide but views it as a violation of the ethical tradition of the profession. Furthermore, after the Oregon vote the ANA formalized two position papers, one on euthanasia and the other on assisted suicide; both oppose active euthanasia. The AMA has continuously opposed PAS. In 1977 it stated, 'mercy killing or euthanasia... is contrary to public policy, medical tradition, and the most fundamental measures of human value and work'. In 1994 the AMA stated that, 'PAS is fundamentally inconsistent with the physician's professional role'. Both the ANA and AMA promote the advancement of techniques and protocols related to pain management and which recognise the patient's request for PAS as a sign that palliative care needs are not being met. Furthermore, the AMA formally condemned the Oregon's Ballot Measure three weeks prior to the referendum.³

Other professional groups in Oregon, such as the Oregon Hospice Association and the Oregon State Pharmacist Association, formally opposed the measure. Contrary to the AMA, the Oregon Medical Association (OMA) took a neutral stand on the measure. The Oregon Nurses Association (ONA) offered debates to inform nurse voters. Following the passage of the Oregon Death with Dignity Act, the ONA developed a position statement which focuses on the nurse's responsibility for reviewing his or her own ethical and moral values as to whether he or she would be involved with the patient's request for PAS (as specified in the law), or if he or she wished to leave that responsibility to others. It went on to recommend that nurses assume the role of advocating patient self-determination. They should assess the patient's mental and physical health status, clarify goals and alternatives, educate patients concerning their legal health care choices, and support both patients and family no matter what choices they make.

Post-referendum events

In response to the demands of citizens following the referendum, Oregon has initiated multiple programmes focusing on improving palliative care, such as improved pain control, better communication, grater compassion, and more control of the dying process by the patient and family. Both physicians and nurses are under intense pressure from both lay and professional groups to increase their competency to treat patients' suffering and their requests for less aggressive end-of-life treatment.

Shortly after the vote, individual hospitals as well as health-care systems developed new or revised policies on the full range of decisions at the end-of-life. Some private facilities banned PAS. Many developed protocols to improve their response to advance directives. The University of Oregon initiated a 'Comfort Care Team', consisting of nursing, medicine, social work,

pharmacy and chaplaincy personnel, directed toward the betterment of the dying experience. The team teaches students in the health-care disciplines a holistic approach to dying patient's care, including pain and symptom control, spiritual and psychosocial intervention, and individual and family support. Nurses assumed leadership roles in advising, consulting and teaching lay and professional groups, including practising physicians and residents. Several State conferences focused on ethical, legal, and care-of-the-dying issues.

Even the Oregon legislature and other political bodies have shown greater responsiveness to resolving barriers to effective palliative care. The State legislature passed *Bill 671* dealing with intractable pain. It prevents the Board of Medical Examiners from taking disciplinary action against physicians who prescribe large doses of narcotics for intractable pain due to chronic or terminal illness. This bill counters the under-prescribing of narcotics for fear of disciplinary action.

Insurance companies in Oregon re-examined their reluctance to fund palliative care. Most now offer hospice benefits and several have liberalised them. Greater physician reimbursement for palliative care resulted in increased hospice referrals by up to one-fifth, which greatly improved the quality of care for many individuals at the end of life. The *Oregon Health Plan* is now available to most older people and disabled persons and the plan covers hospice care at the end-of-life.

An impressive response to the Assisted Suicide Bill was reflected in academia and research on end-of-life issues. A coalition was formed of scientists from the State Division of Health, universities, hospitals, and research centres to study and investigate issues surrounding care of the terminally ill. Several large grants were awarded to the Center for Ethics in the School of Nursing at Oregon Health Sciences University to study end-of-life care and associated ethical issues. A National Advisory Committee was composed of nationally recognised scientists representing many disciplines. While most of the research is in progress, some studies have already reported.

Implications

Nursing has traditionally focused on the care of the total person and the family, thus nursing has assumed leadership in Oregon's quest for improved care of the dying. The research programme is housed in the College of Nursing and is under the direction of a nurse researcher. Understanding the critical distinction between following a patient's wishes for withholding suicide offers a challenge and opportunity for those in the health professions. The public vote supporting PAS has not divided the health professions for or against PAS, but rather has stimulated unprecedented professional investigation, collaboration and education to improve the care of persons in the last phase of life.

Rather than heralding the adoption of PAS by other States, there seems to be greater caution throughout the United States. This is allowing the development of clinical practice and research models to improve end-of-life care. Lastly, the debate since Oregon's ballot was passed has pointed to the overwhelming deficiencies in research and in the clinical, organisational, and legislative frameworks to support effective palliative care for the dying.

Comment

Physician-assisted suicide or voluntary euthanasia has become a contentious issue around the world. Legalised physician-assisted suicide exists in few countries, Netherlands being the most frequently discussed. While some data indicate that a large number of people are in favour of active euthanasia, it is clear that many do not differentiate between advanced directives and PAS. Furthermore, few have adequate knowledge of this complex issue as it relates to end-of-life care and its implications for individuals and families.

In addition to the AMA and ANA, other American groups and organisations, such as the National Hospice Association and the American Association of Homes and Services for the Aging, have issued papers on ethical and patient-care issues related to the last phase of life. Perhaps the time has come for health-care groups and hospices to form an alliance and a commitment to improving pain and symptom control, as well as to comfort and support both patients and the families.

Consideration of the most vulnerable groups such as the older and disabled people should be of the highest priority, since information from The Netherlands already indicates that about one-quarter of those who experience euthanasia had not requested it. Coalitions for disabled people in the United States have already spoken out against PAS. Several periodicals read by older adults have also opposed the practice and are in favour of supportive palliative care.

Medical and nursing education in the United States have significantly neglected the preparation of practitioners to relieve suffering and the symptoms of terminal illness and to provide psychosocial support for patients and families. Since these issues greatly influence how people die all over the world, an international initiative should be started. The outcome of the proposed pro-euthanasia legislation may be the catalyst for governments, professionals and health-care providers to examine seriously current end-of-life care and to make dramatic changes.

NOTES

- American Medical Association Judicial Council. 1977. Terminal illness. In: Proceedings of House of Delegates: 126th Annual Convention. American Medical Association, Chicago.
- 2. American Medical Association Council on Ethical and Judicial Affairs. 1994. Physician-assisted suicide. *Code of Medical Ethics Reports* No. 59, 5 (2).
- AMA's national board opposes Measure 16 (editorial). The Oregonian, Oct. 22, 1994.

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Older People and Policy Issues in Europe Tony Maltby

J. Berghman. 1997. The resurgence of poverty and the struggle against exclusion: a new challenge for social security in Europe? *International Social Security Review*, **50** (1), 3–21.

P. Hennessy. 1997. The growing risk of dependency in old age: what role for families and for social security? *International Social Security Review*, **50** (1), 23–39.

Richard Hugman. 1996. Health and welfare policy and older people in Europe. *Health Care in Later Life*, **1** (6), 211–222.

The selected articles all focus upon issues which are of major concern to policy makers in Europe, at both national and European Union levels. The starting point of this debate is often a restricted view of the 'problem' of the demographic ageing of the population. It has often produced alarmist scenarios to support social policy solutions which withdraw the state from social provision in favour of market-oriented responses.

The paper by Richard Hugman is published in a new journal in which many readers will find other articles of interest. Hugman provides a review of the literature which is carefully crafted to argue the case for the 'welfare mix' model to be used less as a theoretical abstract and more as an aid to pragmatic solutions to the provision and 'development of good quality appropriate services for older people' (p. 221). The paper begins by reviewing the demographic crises debate, taking into account the (so-called) threat that such a trend may have in creating what Estes has referred to as 'age war'. He clearly positions himself with the sceptics by suggesting, correctly in my view, that the arguments for welfare retrenchment in the face of such demographic shifts, should reside in the 'realm of ethics and politics' (p. 214), and that the threat to the provision of health services must be seen as a value judgement.

Nevertheless, he argues that an ageing population may create challenges to health policy throughout Europe, a judgement I do not entirely share. He suggests that the shift towards 'community care' or 'ageing in place', has raised a range of questions for both policy makers and practitioners. These can be located around the trio of 'location (where), duration (when) and formation (how)' (p. 216). After outlining the 'welfare mix' model, he suggests that consideration be given to greater employment of the concept in planning health and welfare services to older people, since it 'goes beyond debates around "threat" or "burden" (p. 221), and allows his trio to be assessed both individually and collectively.

The papers from *International Social Security Review* (ISSR) are published versions of papers given at the major conference, 'Adapting to New Economic and Social Realities: What Challenges, Opportunities and Tasks for Social Security?', in Aarhus in late November 1996. Hennessy's paper complements Hugman's by providing a review of the recent trends in the organisation and financing of long term care, with special attention to the role of families (as care-givers) and social security. He situates his discussion within the recent

reforms of several countries and with particular attention to the German and Austrian reforms. The paper proposes a range of standards by which both present and proposed solutions to this specific 'problem' can be assessed. I was amazed at the somewhat ageist assumptions of the first of these, that long-term care should be regarded as a 'normal risk of living and growing old' (p. 37). Nevertheless the others, focusing finance on the most 'catastrophic costs'; that any reform should balance the response to individual needs against finance and towards community provision; and that the reform should be affordable in terms of the overall societal costs seem apposite and sensible. However, his paper concludes rather weakly, by stating that a larger proportion of national resources should be devoted to long-term care provision. The principal question for him remains how this cost burden can be equitably distributed.

The other *ISSR* article, by Berghman, considers the demographic burden from a social security focus. Berghman's paper firstly provides from a European perspective a useful overview of the debate on poverty and (the more widely-used term) 'social exclusion'. Within this discussion, he raises important and interesting arguments concerning the justification for social security, which has been the traditional route for the alleviation of poverty. He notes that increasingly the trend is to use market solutions, variously called 'privatisation' or 'marketisation' by commentators. He then suggests, based upon his own research, that in The Netherlands, what is deemed as privatisation 'is not necessarily genuine privatization' (p. 8) and points to the shortcomings of social security policy in tackling social exclusion.

Faced with this well-argued case he suggests that the problems confronting European states must be addressed and that the solutions should be 'discussed, agreed and monitored at the European Union (EU) level' through the principle of 'subsidiarity'. At the same time they should reflect 'national and local circumstances' (p. 18). I wonder if this is a realistic and pragmatic solution.

Comments

All the articles reflect a general perception that the demographic trend towards an ageing Europe will pose a number of policy dilemmas. Yet as has been shown, the so called 'demographic time bomb' is largely a myth (Walker, 1996; Walker and Maltby, 1997). Although the changing demographic make-up of European populations requires social policy which can offer practical solutions, the debate has started off on the wrong foot. There needs to be the transformation in our thinking about the 'problems of older people'. We need the development of more inclusive decision-making structures so as to break down the barriers between policy makers and older people, towards a model which would include older people in the decisions themselves. Indeed, one wonders how much input there was in Aarhus from organisations working for older people as well as older people themselves? As we have argued in our book *Ageing Europe* (Walker and Maltby 1997), this would yield substantial benefits not only for older people themselves but also for European society as a whole. It would maintain and possibly increase the

current high levels of solidarity between generations, unleash a large source of talent in the third age for productive use, and ensure that all older people achieve a minimum standard of human dignity. At the same time, increasing the length of healthier lives would help to contain the costs of pensions and health care.

References

Walker, A. 1996. From acquiescence to dissent? A political sociology of population ageing in the United Kingdom. In Minichiello, V., Chappell, C., Kendig, H. and Walker, A. (eds), *Sociology of Aging*. International Sociological Association, Melbourne, Australia.

Walker, A. and Maltby, T. 1997. Ageing Europe. Open University Press, Buckingham.

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