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**Dying with dignity: A project for palliative
care of terminal patients**

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ΣΥΝΤΟΜΗ ΠΕΡΙΛΗΨΗ

Στις μέρες μας, ολοένα και περισσότερα άτομα διατυπώνουν την άποψη ότι έχουν δικαίωμα σε έναν αξιοπρεπή και όσο το δυνατό ανώδυνο θάνατο. Οι διεθνείς οργανισμοί καθώς και οι ιατρικές οργανώσεις, έχουν κατά καιρούς προσπαθήσει να προσεγγίσουν το όλο ζήτημα, με τρόπους μάλλον επιφανειακούς και στο μέτρο του δυνατού, να αποφύγουν να θίξουν την ουσία του θέματος. Σύγχρονες μελέτες δείχνουν αυτήν την αυξητική τάση που διαμορφώνεται στην παγκόσμια κοινωνία. Μια τάση, δηλαδή, υπέρ της ευθανασίας, ως μέσο για έναν αξιοπρεπή και ανώδυνο θάνατο. Τα ζητήματα, ωστόσο, που τίθενται είναι ιδιαιτέρως σοβαρά και χρήζουν προσεκτικής προσεγγίσεως καθώς, όπως εύκολα είναι κατανοητό, μια επιπόλαια προσέγγιση αυτών, δύναται να οδηγήσει σε κακή χρήση της ευθανασίας. Σε κάθε περίπτωση, αφού το όλο ζήτημα προσεγγισθεί από απόψεως ηθικής, θα πρέπει να τεθούν αυστηροί κανόνες με βάση τους οποίους θα γίνεται η όλη διαδικασία.

ABSTRACT

The international palliative care community has articulated a simple but challenging proposition that palliative care is an international human right. International human rights covenants and the discipline of palliative care have, as common themes, the inherent dignity of the individual and the principles of universality and nondiscrimination. However, when we consider the evidence for the effectiveness of palliative care, the lack of palliative care provision for those who may benefit from it is of grave concern. Three disciplines (palliative care, public health, and human rights) are now interacting with a growing resonance. The maturing of palliative care as a clinical specialty and academic discipline has coincided with the development of a public health approach to global and community-wide health problems. The care of the dying is a public health issue. Given that death is both inevitable and universal, the care of people with life-limiting illness stands equal to all other public health issues. The International Covenant on Economic, Social and Cultural Rights (ICESCR) includes the right to health care and General Comment 14 (paragraph 34) CESCR stipulates that “States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons,

to preventive, curative and palliative health services.” However, these rights are seen to be aspirational rights to be achieved progressively over time by each signatory nation to the maximum capacity of their available resources. Although a government may use insufficient resources as a justification for inadequacies of its response to palliative care and pain management, General Comment 14 set out “core obligations” and “obligations of comparable priority” in the provision of health care and placed the burden on governments to justify “that every effort has nevertheless been made to use all available resources at its disposal in order to satisfy, as a matter of priority, [these] obligations.”

THE CURRENT SITUATION

Many developed countries have established palliative care services, most of these services are voluntary, nongovernmental services and do not receive the attention or funding support of government.³ Most countries do not have palliative care policies or integrated palliative care services. Clark and Wright of the International Observatory on End-of-Life Care have mapped palliative care provision worldwide and have categorized palliative care provision on four levels: no activity yet identified, capacity building activity, localized provision, and approaching integration.

They recognize the broadness of these categories and comment, for example, that Pakistan (in the localized provision category) has one hospital-based palliative care service for the whole country, serving a population of 158 million. South Africa (approaching integration) has well-established, nongovernmental organization (NGO) services, although not yet country-wide, and a few hospital-based services integrating palliative care into the formal health care sector. Within the African region, generally, coverage is confined to centers of excellence, although palliative care initiatives to advocate for opioid availability have had some success. Radbruch et al. notes that even in countries

with an adequate standard of care and well developed health care services, access to palliative care is greater in urban areas and for particular patient groups, such as cancer patients. Access to comprehensive home-based palliative care in the United States is limited to patients with a life expectancy of less than six months, an artifact of the health insurance reimbursement system; hospital-based palliative care services are growing in number but may or may not be linked to service delivery in the home or to care provided by home hospice programs during the period before death. Clinicians who perceive palliative care to be terminal care only, with withdrawal of active treatment as opposed to active management of the disease process, control of distressing symptoms, psychosocial and spiritual support-deny their patients the comprehensive care they require when facing the diagnosis of life-threatening illness. Thus, many human immunodeficiency virus (HIV) patients do not receive palliative care, as their clinicians believe that with antiretroviral treatment, palliative care will no longer be necessary. This, despite the fact that patients on antiretroviral treatment still suffer from distressing symptoms and may still die (2.9 million HIV patients died in 2005).

SCOPE OF THE PROBLEM

The World Health Organization (WHO) estimated that in 2002, 57 million people died, 7 million of whom died of malignant neoplasm. Franks et al. estimated that, in the United Kingdom, 25% of people with advanced cancer will require inpatient palliative care and 65% will require home-based palliative care. Add to this 2.9 million people who died of AIDS-related illness during 2005, many in developing countries with resource constraints in delivering health care in general, and the scope of the problem starts to unfold. The statistics provide a concept of the magnitude of the problem but not the length or severity of the illness before death. Moreover, throughout the world, there are growing numbers of individuals who suffer and die from end-stage cardiac, respiratory, renal, and hepatic conditions and life-limiting neurological conditions. These people are likely to experience problems that also would benefit from palliative care.

HUMAN RIGHTS COVENANTS

Both palliative care and human rights are based on principles of the dignity of the individual and the principles of universality and nondiscrimination. To palliative care personnel, this creates a self-evident premise that palliative care is a human right. However, we need to look closely at the history of human rights development and the human rights covenants that have been established to pursue this claim. The International Bill of Rights comprises the UN Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the ICESCR. Article 25.1 of the Universal Declaration of Human Rights states, “Everyone has the right to a standard of living adequate for the health of himself and his family, including food, clothing, housing and medical care and necessary social services.” The ICESCR Article 12.1 asserts that “the State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”

The ICESCR is seen as aspirational in that, in resource-constrained settings, these rights may not be immediately attainable but State Parties that are signatories of the ICESCR commit to progressive realization of the right to health over a period of time and to reporting

on the steps taken to reach this goal. It is also recognized that the right to health includes a number of socioeconomic factors “such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.”

This raises the question of how to prioritize a population’s socioeconomic needs in working toward the realization of the rights articulated in the ICESCR. General Comment No. 14, issued by the committee that oversees the ICESCR, asserts that “in particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services;” General Comment No 14 further describes (in the section on older persons) “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”

Thus, palliative care is already articulated as a human right within the International Bill of Rights. Some countries have taken this further and included palliative care in official documents. In 2000, a Standing Committee of the Canadian Senate proclaimed that end-of-life care was

a right of every citizen. In 2003, the European Committee of Ministers adopted a recommendation, which stated, in part, “palliative care is an inalienable element of a citizen’s right to health care.” The South African Department of Health’s Patients’ Rights Charter describes access to health care: “Everyone has the right of access to health care services that include: iii. Provision for special needs in the case of patients in pain, persons living with HIV or AIDS patients; v. palliative care that is affordable and effective in cases of incurable or terminal illness.”

STATEMENTS FROM THE INTERNATIONAL PALLIATIVE CARE COMMUNITY

The international palliative care community has made a number of key statements, including the Cape Town Declaration (2002), the Korea Declaration (2005), and the Budapest Commitments (2007). The consensus is a call to governments for:

1. the creation and implementation of palliative care policies;
2. equity of access to services, without discrimination;
3. availability and affordability of critical medications, including opioids;
4. the provision of palliative care at all levels of care; and
5. the integration of palliative care education at all levels of the learning continuum from informal caregivers to health professionals.

EUTHANASIA IN THE DEVELOPPED COUNTRIES

Within developed nations, there is increasing public debate about and apparent endorsement of the appropriateness of euthanasia as an autonomous choice to die in the face of intolerable suffering. Surveys report socio-demographic differences in rates of acceptance of euthanasia, but there is little in-depth analysis of how euthanasia is understood and positioned within the social and moral lives of individuals, particularly those who might be considered suitable candidates for example, terminally-ill cancer patients. During discussions with 28 such patients in Australia regarding medical decisions at the end of life, euthanasia was raised by 13 patients, with the others specifically asked about it. Twenty-four patients spoke positively of euthanasia, 19 of these voicing some concerns. None identified euthanasia as a currently favoured option. Four were completely against it. Endorsement for euthanasia was in the context of a hypothetical future or for a hypothetical other person, or temporally associated with acute pain. Arguments supporting euthanasia framed the issue as a matter of freedom of choice, as preserving dignity in death, and as curbing intolerable pain and suffering, both of the patient and of those around them. A common analogy featured was that of euthanising a dog. These

arguments were typically presented as self-evident justification for euthanasia, construed as an appropriate choice to die, with opposers positioned as morally inferior or ignorant. The difficulties of ensuring 'choice' and the moral connotations of 'choosing to die,' however, worked to problematize the appropriateness of euthanising specific individuals. We recommend further empirical investigation of the moral and social meanings associated with euthanasia.

Within democratic industrialized nations, discussion regarding medical assistance in attaining death has achieved increasing momentum, beginning in the 1970s and showing no signs of abating¹. These nations share a number of characteristics: access to sophisticated medical infrastructures, substantial proportions of the populations living beyond 70 years and dying from degenerative or chronic diseases characterized by sustained periods of medical intervention and a gradual decline in function². These democratic nations also take autonomy to be the pre-eminent value in medical practice, asserting the rights and responsibilities of the individual to determine their medical treatment, and to refuse treatment even when this might result in their death³. Simultaneously, individuals expect that the medical profession will ensure a comfortable death⁴. The combination of these factors has

prompted conclusions that the current focus on euthanasia is the logical consequence of cultural assumptions that doctors are obliged to ensure that patients die in circumstances that are acceptable to them¹.

INTERPRETATIONS OF EUTHANASIA-DISCUSSION

Euthanasia, however, means different things to different people^{5,6}. It is often sub-categorized into active vs. passive (which refers to the provision or not of specific medical treatments) and voluntary vs. non-voluntary vs. involuntary which refers to the degree to which the wishes of the one dying are known and determinative)⁷. Although a commonly accepted definition refers to 'a doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request'⁸ or active voluntary euthanasia, lack of agreement regarding definition has been noted as complicating accurate assessment of the practice of, and support for, euthanasia^{5,9}. In addition, 'euthanasia' sometimes includes the provision of pain relief to the point of terminal sedation, otherwise known as the principle of double-effect¹⁰. Critically, although some treat these practices (excluding involuntary euthanasia, deemed homicide) as practically and morally equivalent^{10,11}, others do not^{8,12}. There is a voluminous medical literature debating the pros and cons of either practicing, or legalizing,

euthanasia⁵. As debate encompasses ethical, medico-technical, legal, and social claims, for and against euthanasia⁷, comprehensive coverage is beyond the scope of this article. Dominant arguments for euthanasia center on patient autonomy and wellbeing¹³; are those against, on the value of life, and potential impact of euthanasia on medical practice and society as a whole¹⁴.

Although the amount and quality of empirical data lag behind academic debate¹⁴, survey or opinion polls suggest that there is increasing public support for euthanasia. A recent survey of 33 European countries found highest level of support in countries espousing the right to self-determination¹⁵. In the United States, more than two-thirds of the population, reportedly favor euthanasia. Questions have been raised, however, regarding the validity of survey results assessing euthanasia support, with studies showing variation dependent on the precise wordings and definitions used. Some writers have observed that opinions that ending suffering is a worthwhile goal and that patient autonomy should be paramount may not equate to support for legalizing euthanasia. Others note that abstracted attitudes may not reflect actual behaviors when faced with a personal choice in the here-and-now¹.

Other studies estimate the incidence of euthanasia (again, often plagued by inconsistencies in definition), and correlation studies report on the characteristics of those supporting or requesting euthanasia. Interestingly, the dominant reason given in support of euthanasia is to avoid intractable pain in the terminally ill, yet psychosocial factors appear as important in the decision-making of persons involved.

These findings are echoed by qualitative analyses of interviews with terminally ill patients, typically concentrating on cancer patients' attitudes towards, or reasons for and against, euthanasia¹⁶. Terminally ill cancer patients are usually identified as most likely candidates for euthanasia and, where it is legally permissible, most likely to be euthanized. In a Norwegian study based upon interviews conducted with 18 terminally-ill cancer patients¹⁶, the authors reported that a positive attitude towards euthanasia did not equate to a personal desire to die, and that patients' wishes for euthanasia typically referred to a hypothetical possibility in the future, usually associated with a fear of future, but not current, pain. During an ethnographic study of 30 cases of euthanasia in the Netherlands, Pool¹⁷ found considerable variation in practice, as decisions emerged in the course of multiple, seemingly idiosyncratic interactions between patients (most with AIDS or cancer),

families, doctors, and nurses. There were, moreover, multiple and sometimes, contradictory interpretations made by all parties about individual acts of euthanasia, during processes leading up to, and after, the patient's death.

These writers and others have stressed the need to further examine the assumptions underpinning professed attitudes, and the significance of surveys of patient and public opinion^{16, 17}. Such calls are echoed by those observing the importance of language in discussions about euthanasia^{12, 17}. In a previous study examining how Australian cancer patients (not considered close to death) talked about the decision not to resuscitate following cardiac arrest (the 'do-not-resuscitate' or 'DNR' decision), we observed that many patients mentioned euthanasia. Some equated DNR issues with euthanasia and some considered a lack of hope as legitimate grounds to perform euthanasia¹⁸.

CONCLUSIONS

Euthanasia is growing in acceptance within the world population. The fact that people, increasingly more, desire an honorable and pain free death, indicates that the global opinion about euthanasia and palliative care policies, in overall, should carefully be revised.

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