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## EDITORIAL

### Palliative care in Europe

Marinela van den Heuvel-Olăroiu, MD, PhD, editor-in-chief PALIAȚIA

The Council of Europe has adopted a resolution of great importance: 'Palliative care: a model for innovative health and social policies' (see under *News*). Palliative care is not a luxury service, but an essential health and social service, especially in an ageing Europe and a basic right of patients. Through this resolution all European states have to show how they are executing palliative health care services.

The right to receive palliative care is in the legislation of many European countries, but the implementation of such legislation is problematic in several countries like Romania. Palliative care services are still underdeveloped in Central and Eastern European countries. Therefore, the EAPC congress in Vienna intends to function as a bridge for the development of palliative care all over Europe.

The need for palliative care will increase in Europe due to the ageing of European societies. Indeed this is a challenge for innovative health and social policies. The quality of palliative care as well as the variation in palliative care services will be important issues in the next decade. To guarantee access, quality and choices in palliative care many dilemmas will arise, but they have to be solved. From Brussels to Bergen Europe is working on it; good initiatives are coming from people from Berlin to Bucharest.

## ORIGINAL PAPERS

### Dignity for the frail elderly: care provisions in the Netherlands

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#### Abstract

The ageing of the population will require special care arrangements for the frail old. Such care arrangements have to endorse the dignity of the frail old.

This article describes the care and provisions for the frail old in the Netherlands. A relatively high proportion of the frail old live in (health) care institutions in the Netherlands. As in most countries, elderly utilise more health care than younger ones.

The need for institutional care is assessed objectively by a central committee. However, the need for care is still high despite the large number of facilities. This results in waiting lists for frail old. This high need is also related to perceived health and social circumstances. Palliative care is a speciality in care for the frail old, who are going to die. Dutch policy on palliative care has resulted in a sharp increase of the facilities for palliative care doubled and involvement of more health care professionals and volunteers.

It is concluded that attention for (new) care facilities for the frail old is an important goal for the future despite the wide array of existing facilities for frail old in the Netherlands. Without such (new) developments the care and dignity of the frail old is endangered.

Keywords: *palliative care, ageing, dignity, care facilities, frailty*

#### Introduction

Ageing of European societies is a major challenge for health policy and health care arrangements. In 40 years the number of persons over 80 years old will double in Europe. Each state should consider to formulate policy on ageing, and especially on care for the frail old. During the last 40 years the Netherlands has formulated an explicit policy towards the elderly. This policy is documented in official documents by the government and has been evaluated from different perspectives (1,2,3) and has been translated into a variety of facilities, institutions and arrangements.

In the seventies emphasis was on independency, although the meaning of the concept was not clear. In the eighties and nineties the main emphasis in the documents is on care for the elderly, especially homes for the aged, nursing homes and home care, and on assessing the need for care and on financing the care. The recent policy document, called 'Policy for the elderly in the perspective of an ageing society' (4), emphasizes the own responsibility also

elderly have to contribute to the society as well as their preparedness to contribute to the society. The central government does not see a major task in coordination of ageing policy; municipalities have to take the lead here. And most important elderly citizens have to be prepared to get less 'security and support' from the state (less pensions, more volunteer work etc.) and to take 'their own responsibility'.

In the nineties, the Dutch government has developed a program to stimulate palliative care, which resulted in the foundation of five regional centres for palliative care from 1998-2003. These regional centres of course might be relevant care provisions for elderly as well as others.

This paper presents an overview of the care provisions for the frail old as they are available in the Netherlands. It focuses on the situation 2002-2004, since data are almost completely available in that period. The paper starts with some general population characteristics on demographic and health of persons of 65 years and over. The need for care and utilisation of health care facilities by the elderly will be described, followed by facts and figures on care facilities and waiting lists. The development of palliative care during the last decade in the Netherlands will be depicted. The paper ends with comments and discussion.

### **Social demographic and health characteristics of Dutch elderly**

In 2003 16,193,000 persons lived in the Netherlands, of which 13,7% (2,220,000 persons) were 65 years and over. The number of people 65 years and older have doubled during the last 50 years as is the case in most West European countries.

Among persons of 65 years and older the number of very old is growing relatively faster during the last decades and the number of elderly is expected to grow also in the future. The number of elderly is expected to grow from 13,7% in 2003 to 18,5% in 2020 and to 22,1% in 2050.

#### *Living independently and in institutions*

In growing older the chances of living independently decrease in the Netherlands. Due to former housing policy and health care arrangements a relatively high number of older Dutch citizens live in institutions, i.e. of all persons 65 years and over 6,3% live in institutions. This percentage doubles for all persons 75 years and over to 12,3% and doubles again for persons 85 years and over to 30,4%. Of Dutch citizens 95 years and over (13.176 persons) 55% live in institutions. The majority of institutionalised elderly lives in homes for the aged and nursing homes (5).

As is well-known from all demographics women outnumber men in growing older starting about equal (1 – 1) at 65 years and becoming 5 women to 1 man at age 95.

Such gender differences are also present when data are compared to institutional facilities special designed for the elderly, i.e. homes for the aged and nursing homes, as shown in table 1.

Table 1- People living in institutions in the Netherlands by gender in 2002 (5)

	Female	Male	Total
Psychiatric hospital	5.000	7.000	12.000
Institutes for mentally retarded	10.000	15.000	25.000
<i>Homes for the elderly</i>	<i>80.000</i>	<i>23.000</i>	<i>103.000</i>
<i>Nursing homes</i>	<i>22.000</i>	<i>7.000</i>	<i>29.000</i>
Other institutions	28.000	20.000	48.000
Total	137.000	80.000	217.000

The higher number of women living in institutions is caused by the numbers of persons living in homes for the aged and nursing homes.

#### *Life expectancy*

In 2002 the life expectation at birth was 80,7 years for women and 76,0 year for men (6). The average age of death was in 2002 78,4 years for women and 72,3 years for men. The average age of the remaining partner was 69,5 for women and 71,1 for men. Again as well known, not only do women living longer, they also live longer alone and so the chance that they have a partner to take care for them in case of dependency is significantly smaller.

Analysis of life expectancy at age 65 shows that men may expect to live 15,3 years and women 19,2 years. And most of these years are expected to be years which the elderly live in good health: over 12 years are expected to be a life without physical limitations (12,1 for men and 12,8 for women) and at least 14 years are expected to live with a good mental health (14,0 for men and 16,4 for women) (7). Data show that people of 65 years have a life expectancy in good experienced health of 9 years (9,3 for men and 9,9 for women). Elderly judge their health less positive as compared to younger citizens. The experienced or perceived health status declines in growing older.

#### **The need for care in the elderly**

It is important to note that in growing older most years still be lived in good health. At the same time the use of health care facilities increases. However, use of care is not per se related to the objective or perceived health status. May be the elderly perceive a bad health status, but still has resources (family, money) to take care for himself. In other cases use of care facilities may occur since the facilities are available and persons who do not need the care per se are admitted. This happened to be the case in the Netherlands in the late sixties and seventies from the last century. Again in other cases persons may perceive a high need of care and want to be institutionalised, but they do not fit the criteria. So a felt need may discongruate with objective need. In the Netherlands the assessment criteria ('objective need') have become more and more selective in the eighties and nineties of the last century.

Another reason, why utilisation data are not identical with need, is that a shortage of facilities exists. This happen be the case in the Netherlands during the late nineties and the beginning of this century, resulting in large waiting lists and long waiting time for elderly in need for care.

#### *Assessment for care*

In the Netherlands the need for care for nursing homes, homes for the elderly and home care is assessed by an independent assessment committee using uniform, national criteria. Citizens themselves, family members and health care professionals may ask for an assessment. Each year the number of requests is monitored. The data show that the number of requests increased from 98.571 requests in 2000 to 143.914 requests in 2003 (8).

Asking for care does not mean the person is entitled to receive this care. The assessment criteria have to be met. Only 6-7% of those who are requesting for home care, nursing home care or care in a home for the aged is not 'objectively' indicated. This figures have raised the discussion in the Netherlands whether the costs of an independent assessment are worthwhile.

#### *Utilisation of medical care facilities*

Medical consumption is higher among elderly as compared to younger age groups (6).

Table 2- Medical consumption of the elderly in the Netherlands in 2002.

	65 years and over	All Dutch
Contact with GP	85%	75%
Frequency if contact GP	6%	5%
Contact with medical specialist	59%	38%
Hospital admission in 1 year	12%	6%
Contact with physiotherapist	23%	17%
Use of prescribed medicines	75%	36%
Use of not prescribed medicine	33%	37%

As known from all health survey studies and health statistics, health complaints and chronic diseases increase with growing older and so is medical consumption. However these increase is on average not so 'spectacular' as some policy makers may want the population to believe. Medical consumption is especially high during the last year of life.

### Facilities, beds and patients

Quantitative data are based on national registers. For the sake of comparison all data are from 2001 (9). Table 3 presents an overview of health care institutions in the Netherlands. The Netherlands has a high number of homes for the aged as well as nursing homes. These facilities are mainly used by older persons.

Table 3- Number of institutions, beds and number of patients of various care facilities in the Netherlands in 2001

	Number	Beds (per 1000 inhabitants)	Nursing days (per 1000 inhabitants)
Hospitals (general, academic, specific)	129	53.247 (3,3)	12.778
Psychiatric hospitals/institutes	76	22.940 (1,4)	7.460
Institutions for mentally retarded	154	35.700 (2,2)	
Nursing homes	333	59.610 (3,7)	20.900
Day care nursing homes		5.263	1.445
Homes for the aged	1.346	109.885	
Home care	192		7.768

The most relevant data for frail elderly are data on nursing homes, homes for the elderly and home care. Therefore, some more detailed data will be presented for these three facilities in table 4 (8).

The data show that care to be delivered in nursing homes is time and personnel consuming as compared to home care; twice as much personnel than patients in nursing homes. In home care almost all personnel is working part-time.

Despite a policy by the Dutch government to reduce waiting lists for needy elderly, the data show that such waiting list is still considerable. The waiting list of homes for the elderly is 20% of the patients in care; in nursing homes it is 10% and in home care 5%.

Table 4-Costs, personnel, number of patients and waiting lists of care facilities in the Netherlands in 2003

	Finance € million	Personnel	Patients in care	Patients waiting for care
Nursing homes	4.292	122.061	66.865	6.942
Homes for the aged	3.526	122.388	139.588	27.844
Home care	2.466	197.190	378.375	19.458

#### *Specialists in care for the elderly*

Medical specialist for frail elderly may include nursing home physicians (also called specialist 'elderly physician'), and clinical geriatricians; the later are recognised as a clinical speciality. In 2000 the Netherlands had 82 clinical geriatricians. Nursing home physician is considered to be a speciality on the same level as family medicine with a special three year training program and a special registration. The number of nursing home physicians was 1.007 in 2000 and 1.161 in 2003. There is a shortage of nursing home physicians.

In 2003 the Netherlands had 8.107 general practitioners (family doctors) and 13.254 physiotherapists. The number of clinical specialists is over 13.000.

#### *Admittance and discharge of patients*

Data on admittance and discharge are from 2003 (8). About a quarter (23%) of patients, who are admitted to a somatic ward in a nursing home, comes from home and two third (67%) come from a hospital. For patients admitted to a psycho-geriatric ward these figures are quite different, i.e. 40% and 20%. From these patients about one quarter (24%) are admitted from homes for the aged.

The majority of the psycho-geriatric patients (80%) die in the nursing home. Patients in somatic wards may be discharged at home (43%) or to other institutions (home for the aged and other nursing home; 17%). About one third (36%) of these patients die in the nursing home.

The majority of patients in nursing home do not live in a private room despite parliamentary request ten year ago. Persons in home for the aged have their own apartment (one or two bed-room).

Over 90% of persons living in homes for the aged are 75 years or over. Most persons (85%) come from their own place; 7 % comes from another institution. Most people, who move to a home for the aged, will die there (73%); 20% moves to a nursing home; only 3% moves back home.

#### **Palliative care**

As mentioned in the introduction from 1998 – 2003 a special program to stimulate palliative care has been executed on request of the Dutch government (10).

#### *Need for palliative care*

About three quarter of the elderly die because of a not acute disease. This does not mean that they all need palliative care, but most of these elderly need some care during the last months of their life. Table 5 presents on estimation of the received care by persons 60 years and over, who died in 2002 (8).



Table 5-Use of care by persons of 60 years and over, who died in 2002.

	Number	%
No care	19.000	15
Informal care at home	26.000	20
Formal care at home	5.000	4
Both formal and informal care	31.000	24
Institutional care	48.000	37
Total	129.000	

In the Netherlands, it is estimated, that about 60% of people who die would need palliative care. Based on information from GPs it is estimated that about 44% receive palliative care. Symptoms which need frequently attention in palliative care are: fatigue, breathless, pain, lack of appetite, nausea and anxiety/depression.

Among family of patients as well as patients themselves there is a large demand for information about palliative care. In the Netherlands 600.000 family members and friends were involved in care taking for terminal ill patients between 1996-1999.

#### *Facilities for palliative care*

*The number of facilities on palliative care are presented in table 6. The data show the enormous increase of palliative care facilities with a hospice based approached between 1997 and 2004 (11). Special nursing homes have more and more specialised units and develop more and more expertise. The Dutch government wants to organise such expertise in regional networks.*

Table 6-Palliative care facilities in the Netherlands

	1997	2004
Almost home houses	3	29
Independent hospices	6	25
Children hospices	0	4
Units in homes for the aged	23	35
Units in nursing homes	3	53
Units in hospitals	2	4
Palliative care at home	0	?

Little is know about the exact numbers of patients who receive palliative care in homes for the aged, nursing homes and hospitals. Palliative care at home exists and is given by home care institutions in cooperation with GPs and clinical specialists. Exact numbers are not known yet.

#### **Discussion and comments**

Much data are available about care in the Netherlands. Most data deal with aspects as number of patients, average time of stay, personnel and costs. Also instruments are developed to measure the quality and/or several types of care delivered, quality of care from client's perspective. However, for different care facilities different instruments or registration are used. This hinders a complete comparison.

As mentioned the policy document on ageing of 2005 indicates that the leading initiative the Dutch government was taking in 1970 and which continued – even if the policy documents had a limited analysis or scope – for 25 years is ending. The arguments are that in a democratic, neo liberal society the state should leave as much responsibility as possible to the citizens. However, among elderly there is a significant number who is not able to take that responsibility due to chronic diseases, lack of income, pain and suffering. It has to be feared that with the prevailing policy and ideology in Europe this category of elderly – as well as other categories of citizens in a very vulnerable position – will not receive the quality of services and support to live and end their lives in dignity.

Individuals and families want to live as independent as possible. However each citizens has to share space, resources and services with others. A large part of these services are that each individual is really in an interdependent position, in interaction with other citizens, organisations and authorities. Indeed, a citizen has to behave responsible for himself and for others (inclusive the state) (12). At the same time, the individual may expect from the state and authorities that these respect his autonomy and support his interdependency. For frail elderly this requires attention and understanding of their specific situation and it requires the presence of service, which may fulfil their special needs. It is the society as a whole – and the state as being responsible for the quality of society – that has to guarantee such understanding and services.

When such services are present individuals may keep their autonomy. Without such services humanity will loose its dignity.

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## CLINICAL LESSONS

### Symptoms management in a case of left intermaxillary joint neoplasm, operated, X-ray therapy, PCT (poly chemotherapy)

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#### Abstract

Skin cancer became the most frequent human cancer. The majority has as starting point the epidermis. Metastasis are frequent at the skin level. In some cases it can expand to other parts of the body.

We know two cancer types non-melanoma: *basal cell carcinoma*, the most frequent, in 75% of cases and *squamous cell carcinoma*, in 20% of cases. The last one is more invasive and spread to other parts of the body and has a bad prognosis, especially in case of late diagnosis or early relapse.

We present the case of a 49 year old patient with left intermaxillary joint neoplasm, with unfavorable evolution because the late diagnosis and the type of cancer which need palliative care. Since treatment for cure was impossible, we focused our care to symptom management (pain control, wound care and anxiety reduction) and support (for patient as well as for families) to optimize quality of life.

The knowledge of this type of medical care, *palliative care*, is prerequisite for all doctors, especially for oncologists, neurologists and general practitioners who are confronted regularly with these incurable or terminal patients. Physicians must see beyond traditional methods of treatment, like managing symptoms and psychological, social and spiritual support with the objective to contribute to the quality of life of the patient.

Keywords: *symptoms, management, pain, palliative medicine, quality of life*

# MANAGEMENT

## Volunteers in palliative, terminal care in The Netherlands

### 2. Organization and tasks

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#### Abstract

This article describes the organisation of volunteers in palliative terminal care in the Netherlands. The basis of each organisation is the local community and numerous volunteers.

The organisations are not-for-profit foundations, which are for 75% subsidised by the government. The tasks of the local organisation are executed by a (volunteer) co-ordinator, supervised by the board (all volunteers) of the organisation. The coordinator ensures the quality of the terminal care by volunteers, takes care for a right mix between volunteers and patients/families and supports the volunteers wherever needed.

In the Netherlands there are 8000 persons working as volunteers in this field; their average time to support patients, who need palliative, terminal care is 105 hours per year. The local organisations have founded a national association, VPTZ, to represent their interests at the national level and to give support to the local organisations when needed. The VPTZ participates in European networks and projects.

*Keywords: organisation of volunteers in care, terminal care, palliative care, co-ordinator of volunteers in care.*

## COMMENTS, DISCUSSION

### Legislation regarding palliative care in Romania

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#### Abstract

##### *Objectives:*

Palliative care still is a rather new issue in Romania, especially for the public health sector. Providing palliative care services are stipulated as compulsory in Patients' Rights Law. The objective of this article is to present and comment the laws about providing palliative care.

##### *Material and method:*

The Romanian Official Monitor and a number of articles about the legislative situation in palliative care are analyzed.

##### *Results:*

There is a discrepancy between the legislation on palliative care and the patients' rights to receive palliative care. This situation already exists for twenty years, due to political changes and the policy incoherence of the Ministry of Health.

##### *Conclusions:*

The Romanian law stipulates the patients' rights to receive specialized medical care till the last moment of life and to die in dignity. However, patients may receive palliative care in some regions where nongovernmental organizations provide this type of care. Only a few hospitals in great cities (universities) have beds for palliative care.

**Keywords:** *palliative medicine, palliative care, quality of life, dignity, patients' rights law in Romania*

## **NEW PUBLICATION**

### **End-of-life decisions in Dutch neonatal intensive care units.**

Verhagen E  
Dissertation, University of Groningen, 2009  
ISBN 978-90-77320-67-9

Despite the rapid technical innovations in neonatology, a considerable proportion of newborns still die shortly after birth. The death of many of these infants is often preceded by an end-of-life decision. End-of-life decisions are medical decisions with the effect or the probable effect that death is caused or hastened. They include the decision to withhold or withdraw life-sustaining treatment, as well as the decision to deliberately end a newborn's life with lethal drugs.

Neonatal end-of-life decision-making is one of the most controversial areas of medicine as it raises all kinds of medical, ethical and legal questions regarding clinical management of severely ill newborns. This dissertation examines these questions and provides a description of end-of-life decision-making practice in the Netherlands based on empirical studies by the author and his colleagues.

The first part of the book covers physician's end-of-life decision-making considerations, including those leading to deliberate termination of life, the role of the parents and the use of medication as a part of end-of-life decisions. In Groningen, the so-called Groningen Protocol is developed as supportive tool for deliberate termination of the life of a severely ill newborn. It includes five key requirements (like certainty of diagnosis and prognosis, unbearable suffering, informed consent, independent second opinion) of due care that need to be fulfilled and additional issues that requires explicit clarification to enable authorities to review the case properly.

The last section covers a comparison of end-of-life decision-making in four Newborn Intensive Care Units in the USA, Canada and the Netherlands. A two dimensional classification system was used to involve the newborn's physiology (stable-unstable) and intensive care interventions (withholding-withdrawing). It was found that death occurred under different conditions in the four units. It is interesting to note that international comparison in this field is possible. Fur sure it is useful to learn from experiences and procedures abroad.

The dissertation ends with a reflection on the key aspects of Dutch neonatal end-of-life decision-making. These decisions are taken very carefully with involvement of all 'stake holders' and can only be taken by consensus. If consensus is not reach the decision is postponed.

## Discourses on Aging and Dying

Chatterjee SC, Patniak P, Chariar VM (eds).  
Sage Publications, 2008, 272 pages  
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The inevitability of aging and dying does not make accepting and adjusting to their truths any easier. In 2005 a conference was held to study these truths from various aspects: philosophical, religious, and social. The presentations of this conference are published in *Discourses on Aging and Dying*. The book comes at a time when, on the one hand, the world is witnessing an increase in the percentage of the aged population, and, on the other, traditional practices of caring for the aged are being replaced by more impersonal, state-driven methods.

In India palliative care is developing recently. The need of palliative care is increasing, since traditional values are changing. However, India has a rich tradition in thinking about life and death.

This well organized discourse explores philosophical traditions—Hindu, Buddhist and Islamic perspectives—to explain the concepts of life and death, and offers strategies for coping with aging and dying. It delves into the ethical issues related to these in the Indian context. India, with its huge population, poor bio-medical facilities and the radically changing attitudes towards the aged, is facing a crisis. The book addresses a pressing problem confronting Indian society: end-of-life care.

Overall the book presents multiple perspectives on ageing and dying with fine examples and case studies. It is organised in three parts.

The first part describes a wide spectrum of cosmologies and religious beliefs from Hinduism, Buddhism and Islam to identify the place of death in human existence. The second part focuses on care for the old, using again the same philosophical, religious context, exploring the existing paradigm and views. The need for a holistic approach to the process of ageing is emphasised. In the third part end of life is the central topic, dealing with decision making processes and the meaning of diseases. A special chapter deals with 'Dying with Dignity'.

## NEWS

### **Resolution by the General Assembly of the Council of Europe *Palliative care: a model for innovative health and social policies* 28 January 2009**

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' member states. Palliative care is a substantial and socially innovative addition to curative, highly scientific medicine, where subjective wellbeing of the patient comes after the goal of curing an illness and which involves therapy-related restrictions and sometimes massive side-effects.

The rapporteur, Mr Wolfgang WODARG, also senator in Berlin, 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. Palliative care is 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.

### ***Committed to People* 11<sup>th</sup> congress of the European Association for Palliative Care, Vienna, Austria, 7<sup>th</sup> – 10<sup>th</sup> May 2009**

The 11th Congress of EAPC in Vienna will take up the lead from the last congress in Budapest in June 2007. The congress venue in the middle of Europe allows for easy access for participants from Central and Eastern European countries, showing the continuous commitment of EAPC towards the development of palliative care in these countries.

### ***'Dignity for the Frail Old: From dilemmas to solutions'*: conference in Bergen, Norway 2-5 September 2010**

The *goal* of this conference is to present principles for better care of older persons with frailty in Europe. This will be reached by analyzing future needs and trends, by exploring openly the dilemmas and by identifying potential solutions to ensure frail older people receive the services and care that they deserve. Dilemmas to be discussed include 'what level of care is needed and what level can society afford', 'the dying old person' and 'tolerance, acceptance or isolation: how do caregivers keep compassion?'