



EUROPE

Better Palliative Care for Older People



FONDAZIONE FLORIANI



ABSTRACT

Most deaths in European and other developed countries occur in people aged over 65, but relatively little health policy concerns their needs in the last years of life. As life expectancy increases, the number of people living to older ages is also increasing in many countries. At the same time, the relative number of people of working age is declining and the age of potential caregivers is increasing. Palliative care is therefore of growing public health importance. Older people have traditionally received less palliative care than younger people and services have focused on cancer. This booklet is part of the WHO Regional Office for Europe's work to present evidence for health policy- and decision-makers in a clear and understandable form. It presents the needs of older people, the different trajectories of illnesses they suffer, evidence of underassessment of pain and other symptoms, their need to be involved in decision-making, evidence for effective palliative care solutions, and issues for the future. A companion booklet entitled *Palliative care - the solid facts* considers how to improve services and educate professionals and the public.

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Front cover: Bicycle at a cathedral by Professor Joan Teno, Brown University, USA

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The World Health Organization was established in 1948 as a specialized agency of the United Nations serving as the directing and coordinating authority for international health matters and public health. One of WHO's constitutional functions is to provide objective and reliable information and advice in the field of human health, a responsibility that it fulfils in part through its publications programmes. Through its publications, the Organization seeks to support national health strategies and address the most pressing public health concerns.

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WHO Centre for Urban Health

This publication is an initiative of the Centre for Urban Health, at the WHO Regional Office for Europe. The technical focus of the work of the Centre is on developing tools and resource materials in the areas of health policy, integrated planning for health and sustainable development, urban planning, governance and social support. The Centre is responsible for the Healthy Cities and urban governance programme.



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The aim of this booklet is to incorporate palliative care for serious chronic progressive illnesses within ageing policies, and to promote better care towards the end of life. A considerable body of evidence shows that older people suffer unnecessarily, owing to widespread underassessment and undertreatment of their problems and lack of access to palliative care. As a group, older people have many unmet needs. They experience multiple problems and disabilities and require more complex packages of treatment and social care. This raises many issues for their families and for the professionals who care for them. High-quality care, matching the standards now provided by inpatient hospice and palliative care services for people with cancer, must be developed for older people with equal needs. New policies and methods of improving care must reach out and influence the experience of older people in hospitals, in their own homes and in nursing and residential homes within the community. This booklet and its companion volume, *Palliative care – the solid facts*, aim to provide policy-makers and others with comprehensive facts about the multiple facets of palliative care and related services. This booklet defines what is known about the needs of older people, using evidence from epidemiology, social studies and health services research. During the review, it became clear that the evidence we have on palliative care is incomplete. There are differences in what can be offered across Europe. For some aspects more detailed and robust information would be desirable, but it is quite simply not available. This booklet provides the most solid information that is available at the moment.

Better palliative care for older people expresses a European viewpoint, but may reflect relevant issues in other parts of the world. It targets policy- and decision-makers within government health and social care, the non-governmental, academic and private sectors, and health professionals working with older people. All these groups will need to work to integrate palliative care more widely across health services, and policy-makers need to be aware of the proven benefits of palliative care. The booklet aims to provide information that will help with this task. It makes recommendations for health policy- and decision-makers, health professionals and those funding research on how services may be developed and improved.

I should like to express my thanks to The Floriani Foundation and to its Scientific Director Dr Vittorio Ventafridda, without whose financial support and tremendous enthusiasm this project would not have been realized. I should also like to thank the Open Society Institute for its initial financial contribution to this project. My deep appreciation goes to all the experts who contributed to the preparation of the booklet, as well as to the European Association of Palliative Care for its technical assistance. Finally, a special word of thanks is due to Professor Irene Higginson and Dr Elizabeth Davies of King's College London for the effective way they drove and coordinated the whole preparation process and for their excellent editorial work.

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PREFACE

Across the world – and particularly in developed countries – the number of older people is increasing, raising many pressing issues for health policy as well as important financial and ethical questions. Changes in the way families live and work can leave older people vulnerable and affect their sense of belonging within society. In spite of existing welfare programmes, very often the real needs of older people – for pain relief, to feel involved and listened to and to enjoy a certain degree of autonomy – are not taken into consideration. Pain, physical suffering, helplessness, loneliness and marginalization can too often become part of everyday experience in the final phase of life.

This booklet from the Regional Office for Europe of the World Health Organization arises from a project aimed at increasing awareness among policy- and decision-makers in health care about the needs of older people and how to promote innovative programmes of care. The contributors, recognized for their work in this area, were asked by Professor Irene Higginson and Dr Elizabeth Davies to do their best to set out the evidence of this neglected problem in our societies and of effective solutions.

Up to now, palliative care has mainly concerned itself with patients suffering from cancer, and here it has been successful in reducing suffering towards the end of life. It is now time for palliative care to be part of the overall health policy for older people and to be an integral part of the services they receive. Such programmes need to be based on the introduction of palliative care delivered by well educated professionals and caregivers work-

ing throughout health care systems within hospitals and nursing homes and in people's own homes. We know how to improve care, and we must now integrate that knowledge more clearly into everyday practice. The care of older people facing their last days must focus on quality of life rather than on simply prolonging life itself.

If decision-makers take into account and apply just some of the recommendations in this booklet, older people and their families and those involved in this project will be greatly rewarded.

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INTRODUCTION

It is no surprise that most deaths in European countries occur in people aged over 65, but it is disconcerting to find little health information or policy concerned with the needs of older people in the last years of life or with the quality of care they receive. Given the changes that population ageing will bring for societies, the relative neglect of palliative care in health policy is of concern.

As life expectancy increases, more people live past 65 years of age and into very old age, thus dramatically increasing the numbers of older people. Patterns of disease in the last years of life are also changing. More people are dying from serious chronic diseases rather than from acute illnesses. Many more people

will therefore need some kind of help with problems caused by these diseases towards the end of life, and the population of people needing care is now simply much older.

Traditionally, high quality care at the end of life has mainly been provided for cancer patients in inpatient hospices, but this kind of care now needs to be provided for those with a wider range of diseases. Older people are more likely to have highly complex problems and disabilities, and need packages of care that require partnership and collaboration between different groups and across many settings. This raises many issues for the professionals caring for them, and requires the expertise of both geriatric and palliative care in finding

ways of supporting older people and their families. Countries need to develop health care services to meet the medical and social needs of this group. Effective care must reach into the hospital, into people's homes and into nursing and residential homes within the community.

The recent WHO report *Active ageing: a policy framework (1)* considers many of the challenges that population ageing raises for policy- and decision-makers, and sets out some of the responses required to maintain the health, participation and security of older people in our societies. The current document is



designed to be part of that response. It sets out evidence for policies for palliative care for older people, arguments for integrating palliative care across health services, and models for effective care solutions that will help with the task. A companion booklet, *Palliative care – the solid facts (2)* considers why palliative care is a public health issue.

Part I of the document describes the implications of population ageing for palliative care needs and why these are a public health priority, while Part 2 describes the needs and rights of older people and their families. Part 3 describes the widespread underassessment

and treatment of older peoples' problems and their lack of access to palliative care. Part 4 summarizes evidence for effective care solutions, including better pain relief, communication and organization of services such as home care and specialist services. Part 5 discusses the key challenges for policy- and decision-makers in the governmental, non-governmental, academic and independent sectors, and finally Part 6 provides recommendations to improve care and so provide the security and dignity older people need towards the end of life.

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2. *Palliative care – the solid facts*. Copenhagen, WHO Regional Office for Europe, 2004.

WHY PALLIATIVE CARE FOR OLDER PEOPLE IS A PUBLIC HEALTH PRIORITY

Ageing populations

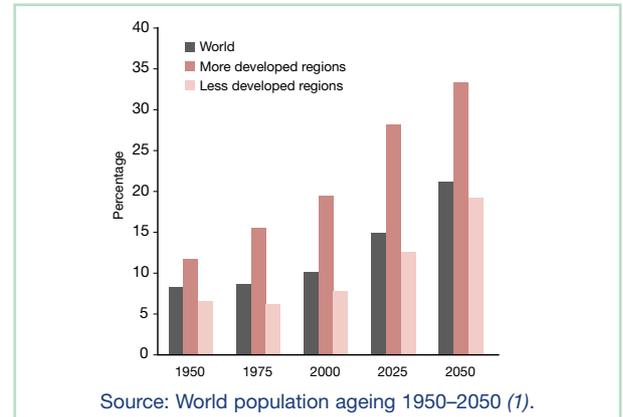
Populations in European and other developed countries are ageing (Fig. 1) (1). Improvements in public health, including the prevention and treatment of infectious diseases, and other innovations have greatly reduced the proportion of deaths occurring in childhood and early adulthood. More people are now living longer and the proportion of those living beyond 60 years has increased, and will increase further over the next 20 years (Table 1) (2). The proportions of older people will vary in different countries. In Japan, for example, more than one in four will be over 65 years of age compared to one in six in the United States.

Table 1 - Percentage of the population aged over 60 in 2000 and predictions for 2020

Country	Year	
	2000	2020
Italy	24	31
Japan	23	34
Germany	23	29
Greece	23	29
Croatia	22	26
Spain	21	27
United Kingdom	21	26
France	21	27
Switzerland	21	32
Norway	20	26
Hungary	20	26
Slovenia	19	29
United States	16	22

Source: United Nations (3).

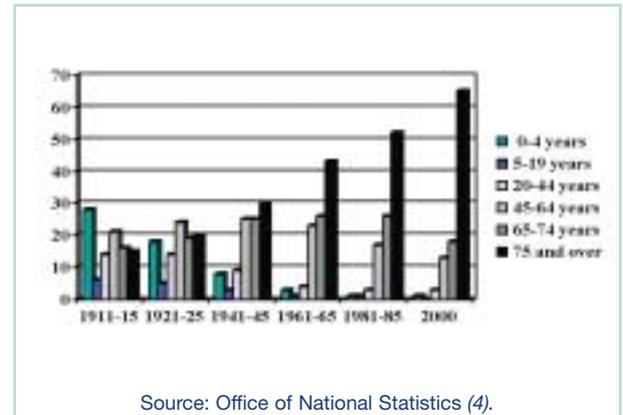
After reaching the age of 65, people now live on average another 12–22 years, with France and Japan having the highest life expectancies. The proportion of people living over the age of 80 is also increasing. In France, Germany, Italy, Japan and the United Kingdom,



Source: World population ageing 1950–2050 (1).

Fig. 1 - Population ageing: population aged 60 and over

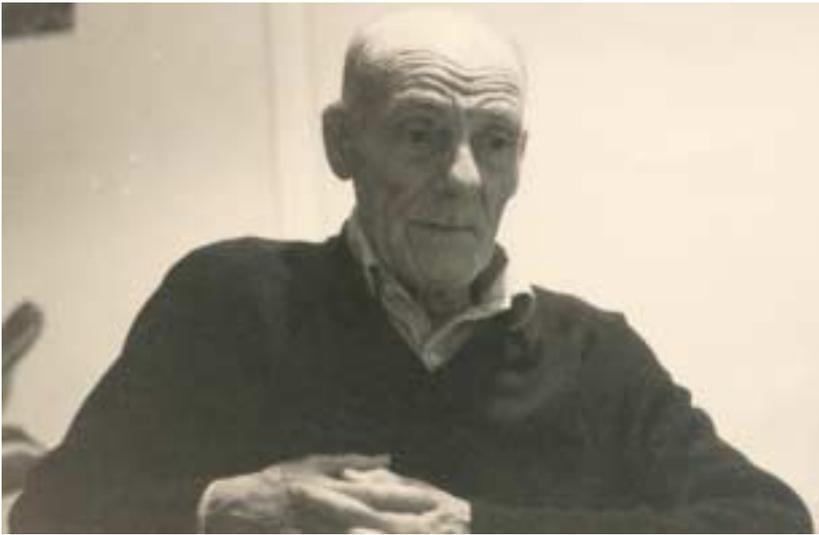
4% of the population is now this old (3). It is predicted that other countries will follow a similar though less rapid trend. Data on deaths in England and Wales, for example, show a dramatic increase in proportion of deaths now occurring at much older ages (Fig. 2).



Source: Office of National Statistics (4).

Fig. 2 - Distribution of deaths by age group, England and Wales, 1911–2000

Women consistently live longer than men, with some figures suggesting that on average they live as much as six years longer, so that nearly twice as many women as men live to 80 years of age.



It is not yet entirely clear whether increased longevity is inevitably accompanied by longer periods of disability towards the end of life (6). Some recent findings and predictions suggest an optimistic picture, with disability declining in successive cohorts of people as they age (7). However, if more people live to older ages, and if chronic diseases become more common with age, then the numbers of people in a population living with their effects will increase. This means that there will be more people needing some form of help towards the end of life. Furthermore, women are more likely to suffer from several chronic conditions such as dementia, osteoporosis and arthritis, suggesting that a greater part of their “extra” survival may be affected by disability (8).

The changing epidemiology of disease

As populations age, the pattern of diseases that people suffer and die from also changes. Increasingly, more people die as a result of serious chronic diseases such as heart disease, cerebrovascular disease (including stroke), respiratory disease and cancer (Table 2) (5). It can be difficult to diagnose with certainty any one disease as the main cause of death, as many older people suffer from several conditions together that might all contribute to death. Dementia is an example of one condition that is regularly underdiagnosed.

Table 2 - Main predicted causes of death for 2020 and previous causes in 1990

Disorder	Predicted ranking 2020	Previous ranking 1990
Ischaemic heart disease	1	1
Cerebrovascular disease (including stroke)	2	2
Chronic obstructive pulmonary disease	3	6
Lower respiratory infections	4	3
Lung, trachea and bronchial cancer	5	10

Source: Murray & Lopez (5).

The increasing age of caregivers

A related aspect of population ageing is a decrease in the proportion of younger people as fertility rates decline. The age of informal caregivers, particularly women who have traditionally been relied on to care for and support people towards the end of life, is therefore also increasing. As the proportion of working-age to older people declines, fewer women (and men) will be able to find the time to provide support and care (Fig. 3). Families have become smaller, more dispersed and varied, affected by increased migration, divorce and external pressures. With few exceptions, families want to be able to provide the best care they can for their older members. Health care systems, however, vary in the degree to which they provide the help that caregivers need at

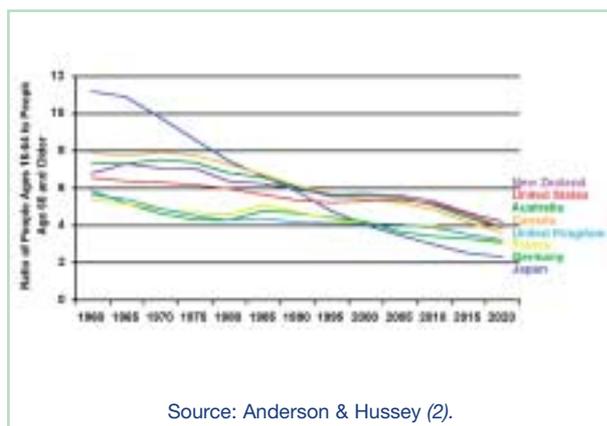


Fig. 3 - The proportions of working-age to elderly people in eight countries, 1960–2020 (used with permission from the Commonwealth Fund, New York)

home or funding for institutional care for people near the end of life. Some families with older members needing full-time care will find the financial cost and burden unmanageable, and it may be intolerable for older women caring for spouses whom they will outlive (9).

Financial implications for health care systems

Undoubtedly, the growing numbers of older people will challenge health care systems to provide more effective and compassionate care towards the end of life. However, population ageing does not necessarily mean that the cost of care for people in the last years of their life will eventually overwhelm health service funding (10).

Health care systems already vary considerably in the proportion of their gross national product spent on health care for older people. International comparisons show no consistent relationship between this proportion and the proportion of older people in the country. Medical advances have increasingly allowed

life to be prolonged at older ages, and this is often seen as an extra expense. Recent studies in the United States, however, have suggested that higher spending is not associated with higher quality care, better access to care or better health outcomes or satisfaction with hospital care (11,12). Interviews with seriously ill patients also reveal that more than one in three who would prefer palliative or “comfort” care believe their medical care is at odds with their preference. This inconsistency between preference and action is associated with higher health care costs, but also with increased survival at one year (13). It may therefore not be the role of health care to seek a cheap solution to the issues that technology and ageing present, but to provide packages of care for people in different situations that properly take account of their wishes.

The range of settings for care

In most countries, most older people live at home, although countries have different approaches to providing long-term care for older people (Fig. 4).

In Australia and Germany, 1 in 15 older people live in institutions, compared to 1 in 20 in the United Kingdom. The lifetime chance of receiving such care may be higher (14). For example, in the United States around half of those living past the age of 80 spend some time in a nursing home. In the United Kingdom most funding for inpatient hospice services comes through the charitable sector, while in the United States such services are funded through federal Medicare benefits. The way in which different health care settings work and the effectiveness of the care they provide inevitably affects what other settings can offer.

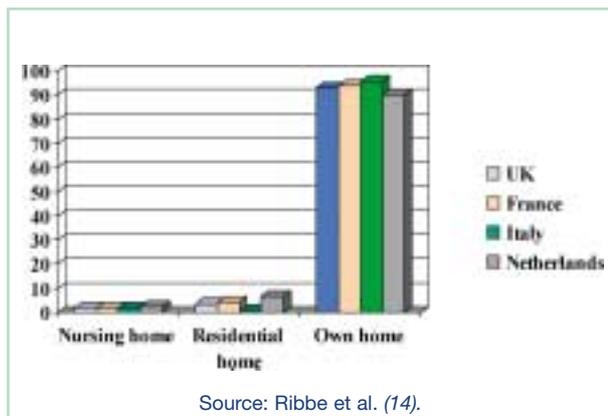


Fig. 4 - Place of residence for people >65 years in four countries

For example, staff shortages and lack of palliative skills for home care and in nursing homes may increase hospital admissions for care at the very end of life.

Developed countries are therefore facing very similar issues, and can learn from each other in different areas.

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PALLIATIVE CARE: THE NEEDS AND RIGHTS OF OLDER PEOPLE AND THEIR FAMILIES

Palliative care

Palliative care was defined by the World Health Organization in 2002 (1), as:

... an approach that improves the quality 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, psychosocial and spiritual.

Palliative care provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, and intends neither to hasten nor to prolong death. Palliative care integrates the psychological and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible until death. It also offers a support system to help the family cope during the patient's illness and in their own bereavement. Using a team approach, palliative care addresses the needs of patients and their families, including bereavement counselling if necessary. It enhances quality of life, and may positively influence the course of the illness. It is applicable early in the course of the illness with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (1,2).

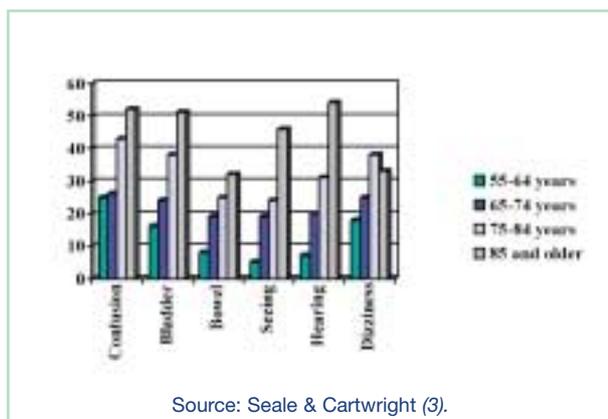
Palliative care should be offered as needs develop and before they become unmanageable. Palliative care must not be something that only specialized palliative care teams, palliative care services or hospices offer when other treatment has been withdrawn. It should be an integral part of care and take place in any setting.



The needs of older people at the end of life

It is no surprise that most deaths in European and other developed countries occur in people aged over 65. None the less, comparatively little research has been carried out on their needs for palliative care. Older people very clearly have special needs, because their problems are different and often more complex than those of younger people.

- Older people are more commonly affected by multiple medical problems of varying severity.
- The cumulative effect of these may be much greater than any individual disease, and typically lead to greater impairment and needs for care.



Source: Seale & Cartwright (3).

Fig. 1 - Age at death and prevalence of problems reported for the year before death

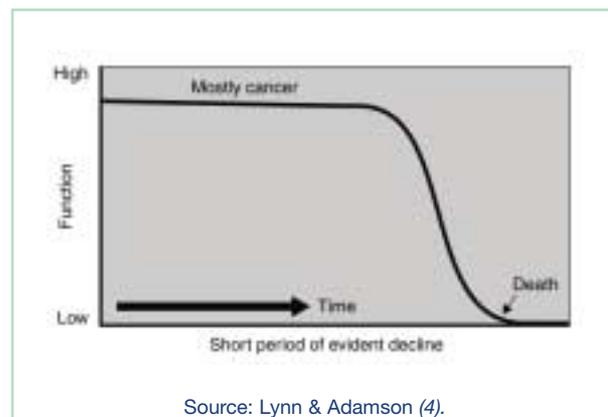
- Older people are at greater risk of adverse drug reactions and of iatrogenic illness.
- Minor problems may have a greater cumulative psychological impact in older people.
- Problems of acute illness may be superimposed on physical or mental impairment, economic hardship and social isolation.

The complexity of the problems that older people have to suffer is revealed by epidemiological studies in which relatives or key informants are asked about the last year of the patient's life (Fig. 1). These show, in particular, that mental confusion, problems with bladder and bowel control, sight and hearing difficulties and dizziness all greatly increase with age (3).

The problems that many older people experience in the last year of life are therefore those of great age and its troubles as well as those caused by their final illness. All areas of health care that seek to provide continuity of care for older people, including general practice, geriatric medicine and rehabilitation, have recognized these wider needs for many years. Because it is more difficult to predict the course of many chronic diseases affecting older people, palliative care should be based on patient and family needs and not on prognosis. The examples of cancer, heart failure and dementia illustrate this point.

Cancer

The term cancer includes many illnesses that cause varying problems depending on the site of the body affected. The disease is more



Source: Lynn & Adamson (4).

Fig. 2 - Model of a trajectory of an illness due to cancer

common with increasing age, and three quarters of deaths from cancer occur in people aged over 65. The most common cancers affecting women are breast, lung and colorectal cancer, while those most commonly affecting men are lung, prostate and colorectal cancer. Breast and prostate cancer have the best prognoses, followed by colorectal cancer and lung cancer. The prognosis for any individual depends on the extent of the growth at presentation and the response of the tumour to treatment, which may include surgery, radiotherapy and/or chemotherapy. People are not usually severely restricted in their activity until the final stages of the illness when the disease stops responding to treatment (Fig. 2), but they have many psychological needs and require information and support from the time of diagnosis. In general, studies show that patients with cancer want more information, would like to be involved in decision-making,

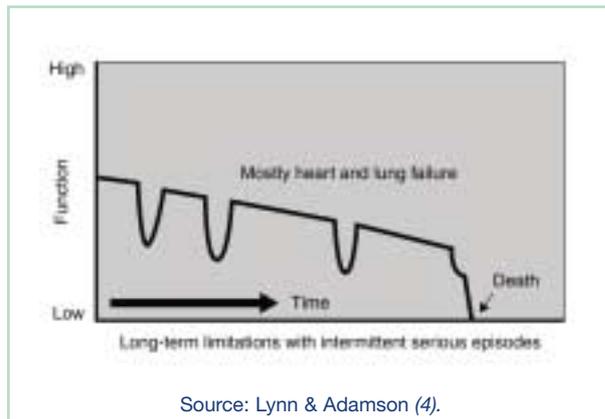


Fig. 3 - Model of an illness trajectory for organ failure such as heart failure

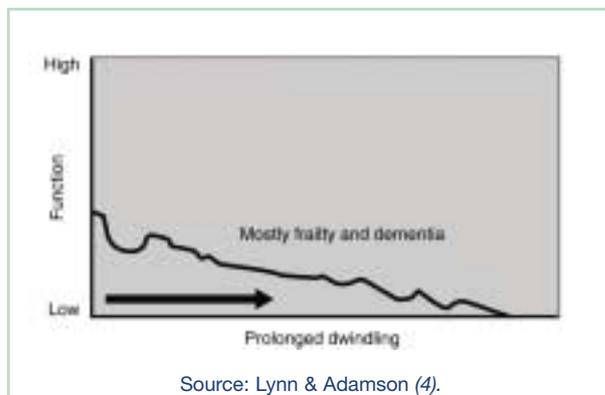


Fig. 4 - Model of an illness trajectory for dementia or frailty

and experience better psychosocial adjustment if palliative care and good communication are part of their care from the time of diagnosis.

Heart failure

Heart failure affects more than one in ten people aged over 70, and the five-year mortality of 80% is worse than for many cancers. The course is often one of intermittent exacerbation of the symptoms of breathlessness and pain, causing great distress, followed by a

gradual return to, or near to, the previous level of function (5). Death may follow a gradual decline or may be sudden during a crisis (Fig. 3). Although there has been considerable progress in treating symptoms and crises well, patients and their families often have difficulty understanding and managing the complex drug regimes required (6). People with heart failure seem to have less formal knowledge of their diagnosis and prognosis. There appears to be a lack of open communication from health professionals about this, probably owing in part to the difficulty of prediction and an unwillingness to raise the subject (7). Families also report poor coordination of care and difficulties in forming a relationship with any single professional (7). These aspects of care therefore compare unfavourably to the information and support available to people with cancer.

Dementia

Dementia affects 4% of people over the age of 70, increasing to 13% of those over the age of 80 (8). The median length of survival from diagnosis to death is eight years, and during this time there is a progressive deterioration in ability and awareness (Fig. 4).

Common symptoms include mental confusion, urinary incontinence, pain, low mood, constipation and loss of appetite. The physical and emotional burden on family members is well documented, as is their grief as they slowly lose the person they knew. Many ethical issues are also raised by the care of people with dementia who are unable to communicate their wishes (9). Current issues include the best use of antibiotics in the treatment of pneumonia and of feeding tubes for hydration and nutrition. However, less than 1% of



patients in inpatient hospices have dementia as their primary diagnosis (10).

The needs of caregivers

Only relatively recently has the role of people caring for older seriously ill people been fully appreciated. There is relatively little formal knowledge about their needs, although their role varies considerably. It may include carrying out intimate tasks such as washing, helping people to dress and go to the toilet, or heavy tasks such as lifting. This kind of caring is usually performed by people with close kinship ties, often living in the same house and motivated by love and a desire to keep an older person out of an institution. However, the burden of care may lead in time to conflicting emotions, dealing with changes in personality and behaviour, restrictions on the carer's own life, and the drain on financial resources. Long-term care for seriously ill relatives is unpaid and unsupported work that may damage the health, wellbeing and financial security of caregivers themselves (11).

A new way of looking at palliative care

As ageing populations develop new needs, health care systems need to be equally flexible

in their response and perceptions about palliative care need to change. Traditionally, palliative care has been offered most often to people suffering from cancer, partly because the course of this illness is more predictable and it is thus easier to recognize and plan for the needs of patients and their families. One consequence

of this has been the perception that palliative care is relevant only to the last few weeks of life and can be delivered only by specialized services (Fig. 5).

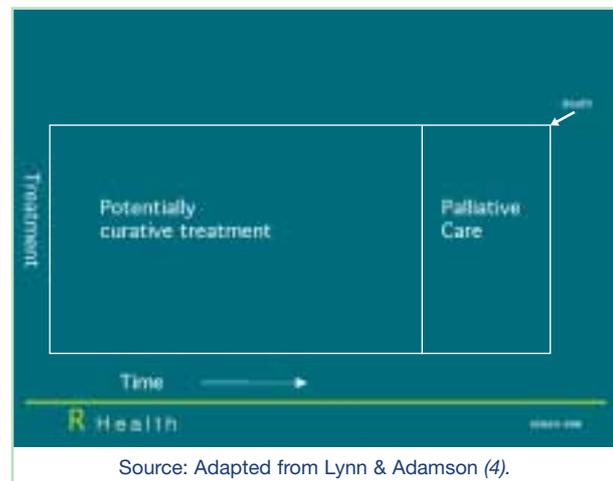
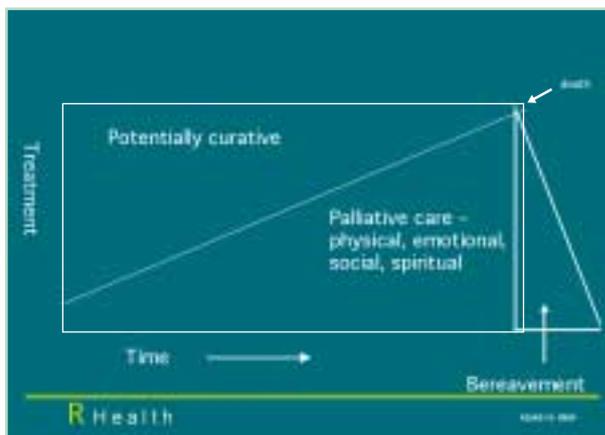


Fig. 5 - Traditional concept of palliative care

In fact, people and their families experience many problems throughout the many years of an illness and need help at the time and not at an easily definable point just before death. The idea that palliative support and care should be offered alongside potentially curative treatment, although obvious to patients and families, appears a radical idea for some health professionals (Fig. 6). In addition to supporting



Source: Adapted from Lynn & Adamson (4).

Fig. 6 - New concept of palliative care

people with a clearly terminal illness, health care systems must find ways of supporting people with serious chronic illness or multiple chronic problems over many years and allow for an unpredictable time of death (12).

Autonomy and choice

Everyone has the right to ... security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his [or her] control.

Article 25, United Nations Universal Declaration of Human Rights, 2001

However complex a person's problems or uncertain their future may be, autonomy is a key human right and maintaining this must be a core ethical value for society and health

services. This has recently been incorporated into the concept of "patient-centred care" that many health care systems are now attempting to implement, which emphasizes the need to structure health care in response to people's values and preferences.

Patient-centred care is care that incorporates respect for patients' values and preferences, provides information in clear and understandable terms, promotes autonomy in decision-making and attends to the need for physical comfort and emotional support (13).

Preferences for place of care and death

There is increasing research evidence concerning the decisions that people would prefer to make about care at the end of their life.



Most studies have found that around 75% of respondents would prefer to die at home. Those recently bereaved of a relative or friend are slightly more likely to prefer inpatient hospice care. A range of studies have found that between 50% and 70% of people receiving care for a serious illness also say they would

prefer home care at the end of life (although as they approach death, part of this group may come to prefer inpatient care (14). A core value for palliative care from its inception has been in enabling people to make genuine choices about their care.

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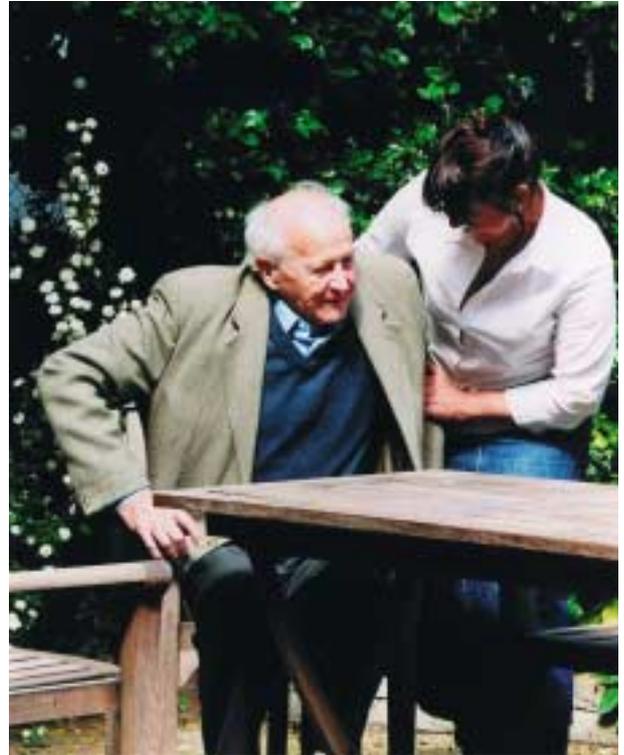
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EVIDENCE OF UNDERASSESSMENT AND UNDERTREATMENT

Despite the fact that older people have varied needs for health and social care at the end of life, there is already evidence that many of their needs are not met. A body of evidence is mounting to show that older people suffer unnecessarily because of widespread underassessment and undertreatment of their problems.

Underassessment of pain

One important cause of individual suffering is pain. Community surveys consistently find that pain is an important symptom in around one third of older people (1). Pain makes people feel less positive about their health, and in around one fifth is bad enough to limit their everyday activity (2). However, older people tend to underreport their symptoms, and physicians in turn tend to undertreat pain in older people, particularly in nonmalignant disease but also in patients being treated for cancer. A large American study of over 4000 cancer patients in nursing homes who reported daily pain found that a quarter received no painkillers of any type. As age increased a greater proportion of people in pain received no pain relief, and judged according to WHO's pain ladder, those over 85 years of age were least likely to receive drugs such as opiates (Fig. 1) (3). A regional cross-sectional study in one region in Italy found that 57% of 4121 hospital patients interviewed had suffered pain in the previous 24 hours. The proportion with pain increased significantly with age (4). Older people with dementia are at particular risk of poor pain control, because their communication problems make them less able to report pain and it is more difficult for their attendants to assess it properly.



Lack of information and involvement in decision-making

There have been consistent findings in the last few decades that cancer services often fail to meet patients' needs for communication, information and support. Systematic reviews find strong evidence that patients value accurate information, that many feel they are given insufficient information, and that doctors and nurses currently have limited ability to detect patients' needs (5). Although there are methodological problems with measures of "satisfaction" and with international comparisons because of differences in expectations, survey data do suggest that patients identify similar kinds of problems in different countries.

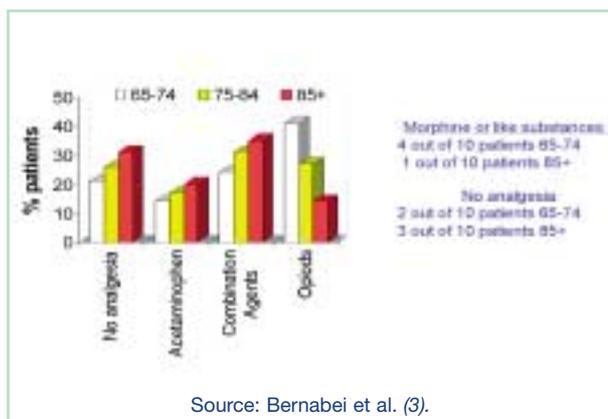


Fig. 1 - Pharmacological treatment of cancer patients for pain in American nursing homes, according to the WHO pain ladder

Salient issues include information and education, coordination of care, respect for preferences, emotional support, physical comfort, involvement of family and friends, and continuity and transitions in care (6). Many studies of people diagnosed with life-threatening illness reveal that the way in which they are given information and are involved in decision-making are important determinants of satisfaction with care. A large American cohort study of seriously ill patients recently confirmed that these factors were also important for families (7,8).

Recent reviews of cancer treatment and care in the United States have revealed widespread variation in treatment and care received by older people, suggesting that they had not received information about the full range of options available (9,10).

Lack of home care

Despite the preference of many people to be cared for and to die at home, in practice death in hospital remains common in many countries (Fig. 2).

The variation in place of death suggests that the organization of services plays an important role in determining the options that people can consider (Fig. 3). This possibility is further

suggested by detailed studies in the United States, which find that the proportion of people dying at home ranges from 18% to 32% and appears to vary primarily with the availability of hospital beds (12). Patient preferences, physician training and availability of community services were either irrelevant to place of death or of minimal importance compared to the number of hospital beds per head of population.

Cultural values are also important. In Italy, for example, where the hospice movement is in its infancy, it is widely recognized that death in hospital is more common in the north of the country while in the south families prefer to care for people at home. The Netherlands has reported some success in providing a range of palliative

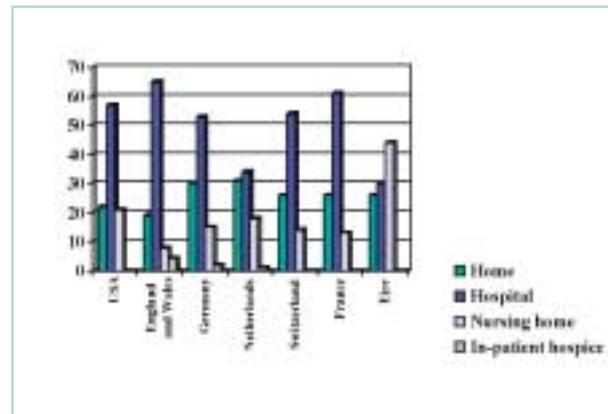


Fig. 2 - Preliminary data on place of death by country

Sources: United States: Weizen SMS et al. (11); England and Wales: Office of National Statistics 2000; Switzerland: extrapolations from Federal Statistics 1985; France: INSERM 1999; Netherlands: Central Office of Statistics in the Netherlands, 2000 (M. Ribbe, personal communication). Eire: J. Ling, personal communication. Germany: T. Schindler, personal communication.

Note: Data from different countries are collected in different ways and sometimes not at all. This has limited the comparison that can be drawn, but highlights the need for health care systems across Europe to begin to collect this information routinely. Some 15% of deaths in the Netherlands also occur in residential homes for the elderly, and these are not included in the graph above.

care services in different settings and in allowing people to die at home if they wish (13).

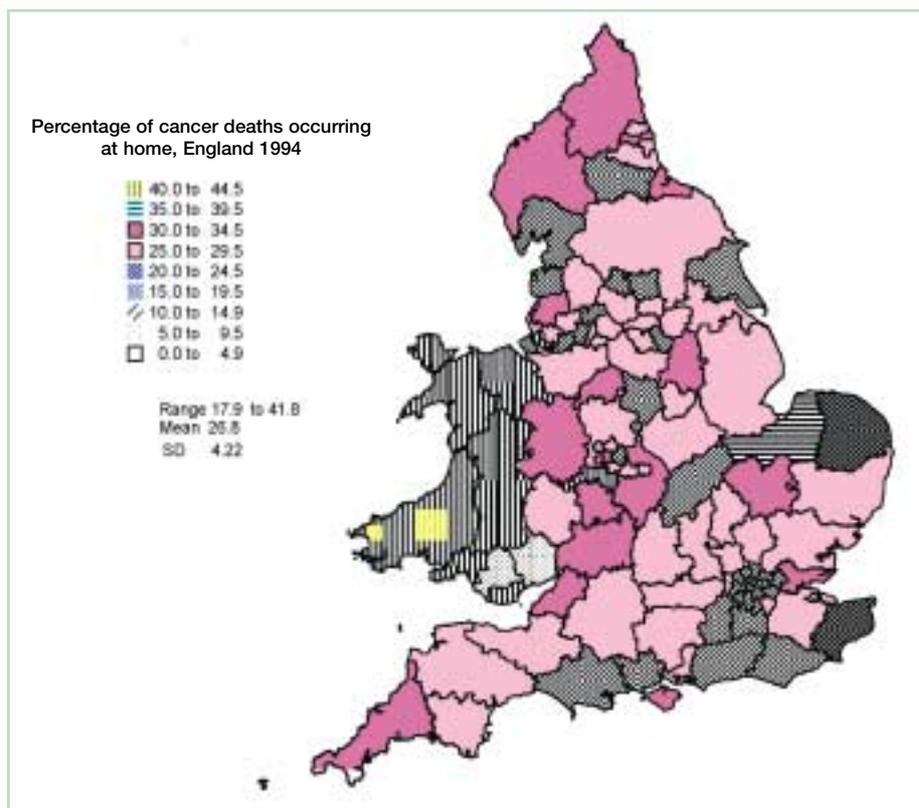


Fig. 3 - Percentage of cancer deaths occurring at home, England 1994, by Health Authority
Source: Higginson IJ Astin P, Doland S, Sen-Gupta G, Jarman B (1997), King's College London.
Note: Wales data not included.

Many countries, however, do not routinely record and collate data on place of death.

Lack of access to specialist services

One reason for older people not receiving palliative care is that they suffer more often from many chronic illnesses such as heart failure and dementia, which have not traditionally

been the focus of specialist palliative care and where models of palliative care are only just beginning to be applied. Nevertheless, even older people with cancer may not have access to specialist palliative care. In England and Wales, for example, older people are under-represented in settings such as inpatient hospices, where high-quality end-of-life care can be offered (14–16). With increasing age they are less likely to receive care for their final illness in an inpatient hospice (Fig. 4). A study in Australia found that 73% of cancer patients under 60 years of age were referred to palliative care services compared to only 58% of those aged over 80 years

(18). Specialist palliative care services in the United States reach more non-cancer patients than many other services, but overall only 17% of all dying people are reached by federally funded hospice services (19). In one analysis, 30% of patients cared for by inpatient hospice services suffered from non-cancer illnesses, most commonly cardiac failure, chronic obstructive pulmonary disease, stroke, dementia and renal failure (18). By comparison, figures for the United Kingdom are far lower (20).

There is relatively little information on the

needs of very old people receiving specialist palliative care in hospital. One American study found that patients aged 80 who were referred to the specialist palliative care service in one hospital were more likely to be women living in nursing homes. They were less likely to have cancer and more likely to have dementia, and this factor was the major influence on their ability to take part in decisions about their care and treatment (21).



Lack of palliative care within nursing and residential homes

Between 2% and 5% of people aged 65 or older live in nursing homes. Mainly, however, these are older people who are frail or with chronic physical or mental disability, and diagnoses commonly include stroke, cardiac failure, chronic pulmonary disease, Parkinson's

disease and dementia. Many people recognize a move to a nursing home as a “last resting place” before death, and many people living in these homes will clearly have palliative care needs (22).

In many countries, nursing homes already play an increasing role in caring for frail older people at the end of life (Fig. 4). In the United States, for example, the proportion of people dying in nursing homes increased from just under one in five in 1989 to one in four in 1997. About half spend some time in a nursing home in the last month of life. People dying in nursing homes

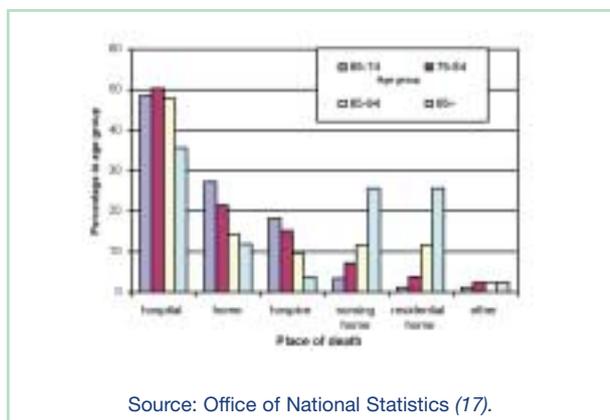


Fig. 4 - Place of death from cancer in older patients, England and Wales, 1999, analysed by Higginson

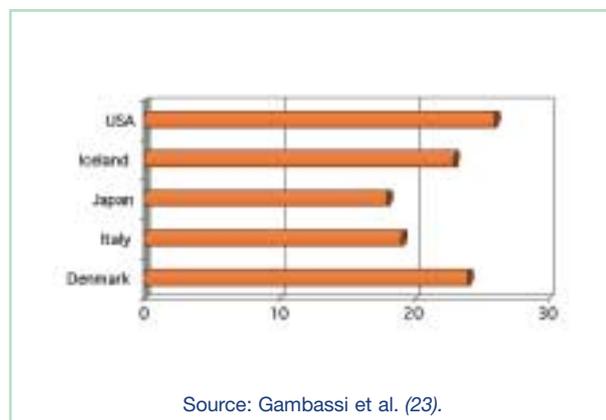


Fig. 5 - Percentages of older people experiencing pain in long-term care: comparison of five countries

are more likely to endure a prolonged period of disability before death than those dying at home. Most residents complain of pain, and data suggest that pain is not well treated and sometimes not treated at all (23) (Fig. 5). Up to two thirds of people living in nursing homes are affected by cognitive impairment and this complicates the assessment and recognition of pain (J.M. Teno, unpublished observations, 2002).

In some countries, nursing homes run rehabilitation programmes. The system in the Netherlands appears to be particularly well developed, with palliative care units sited in 13% of nursing homes. In the United States, nursing home patients enrolled in palliative care programmes delivered by hospice services received better pain control than other residents (24).



Generally, however, little is known about the quality of end-of-life care received in nursing homes, and issues of concern include staff shortages, high staff turnover and lack of palliative care skills (22).

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EVIDENCE FOR EFFECTIVE CARE SOLUTIONS

As the hospice and palliative care movement has expanded, evidence has grown for the effectiveness of aspects of the treatment and care it has promoted. Systematic reviews of the evidence, including studies on people with cancer from many different countries, now report consistently the importance of certain key areas of care. The evidence is currently strongest for simple measures such as pain relief, good communication and coordinated teamwork to satisfy preferences for place of care. There is also preliminary evidence for the application of models of palliative care for people with other illnesses (1).

Palliative care skills of individual health professionals

Pain and symptom control

The effectiveness of pain control methods has been established for over 30 years, and a wide variety of drugs is available to control pain associated with cancer and other illnesses. Observational studies show that, when clinical guidelines on pain control are followed, 70–97% of patients with advanced cancer gain adequate pain relief. Research on implementation has been relatively neglected, but education can improve the knowledge and attitudes of staff about pain (though not necessarily the levels of pain suffered by patients). There is most evidence for brief interventions, whereby nurses encourage patients to complete pain diaries and doctors use explicit strategies to ensure that pain is assessed daily and that drug dosages are adjusted accordingly (2). By comparison, the study of pain using standardized measures in older people with other illnesses has been relatively neglected.

Communication skills

Effective communication between doctors and patients is associated with a range of health outcomes including, most commonly, improvements in psychological health, symptoms and function and better control of pain, blood pressure and blood glucose level (3). The ability of health professionals to communicate effectively with families and involve them in decision-making consistently emerges as an important contributor to their satisfaction with care at the end of life (4). The communication skills of health professionals can be improved by using feedback from videotaped consultations and discussion, but they nevertheless need further help to sustain these new skills in everyday practice (5).

Giving information

Recordings or summaries of key consultations are of benefit to most cancer patients. They lead to improved knowledge and recall of information without causing psychological problems (6) and to greater satisfaction (7). Nevertheless, these must be used sensitively with patients whose prognosis is poor, and account must be taken of whether or not they wish to know the full facts (5). In general, decision-making aids can help professionals deal with the concerns of patients, explain their treatment and improve their satisfaction (5,8).

Providing holistic care

Spiritual support

Spiritual and religious needs are highly personal and salient to many people at the end of life, and therefore need to be part of palliative care services. There is some preliminary evidence that spiritual belief can affect the way in



which patients cope, and even the outcome of the disease. It can also affect the way in which relatives cope with bereavement (9,10).

Psychological support

A wide range of psychological interventions has been tested in over 150 randomized trials over 40 years. The results were mixed and tended to vary by site of disease and follow-up period, with positive outcomes not being sustained over time. Most evidence exists for adjuvant psychological therapy, but more work is required to identify specific needs and how to target patients for intervention (9,11).

Complementary therapy

In the general population, complementary therapies tend to be used by younger women who perceive them as natural and allowing

greater control. Despite interest in their use in palliative care, studies have so far been hampered by a lack of standard definitions, small sample sizes, poor response rates and inadequate measurement, and thus no adequate conclusions have been drawn (9).

Coordinating care across different settings

Transferring information

An important issue in the care of older people is the transfer of information between settings, and between those with responsibility for medical care and those providing medical and social support services in the community. Current mechanisms are often inadequate and – although there is little empirical research in the area – a “key worker”, “case manager” or “case coordinator” seems the most effective way of transferring information (9,12).

Meeting preferences for home care

A second issue is whether improved coordination of care can allow more patients to die at home if they so desire. Trials of different approaches to coordinating hospital and community services are now finding that a higher proportion of people can be helped to die at home if they wish. There is also evidence that the quality of life of their caregivers can be improved if support is provided and well coordinated (10).

Supporting families and caregivers

A range of services has been developed, including home care, respite and “sitting” services, activities within social networks, support groups and individual psychotherapy or education. Carers generally report satisfaction with home care and, if they are willing to

leave the patient, value respite and sitting services. The few who take up group activities or support groups value the chance to talk openly with others, but formal evaluation of their benefit is weak. Further work is needed to explore the priorities of caregivers and what it is realistic for services to achieve for them (13). Here it is important to remember that giving caregivers the impression of being listened to and appreciated is in itself an important goal of care.



Anxiety and depression are normal responses to loss and the threat of loss in lifelong relationships. Health professionals who meet people at the very end of these relationships may not be able to influence these basic responses. Nevertheless, they can avoid adding a sense of isolation or confusion by providing care that appears coherent and coordinated and that relieves the patient's suffering.

Specialist palliative care

Specialist palliative care teams

A common model for delivering palliative care has been to concentrate expertise in multiprofessional teams that work in hospitals, inpatient units such as hospices or within the community. These teams usually deal with a selected group of patients, referred to them by other teams of professionals, who have the most complex needs for symptom control, communication and coordination of care.

Despite conflicting findings in initial reviews, meta-analysis now reveals benefits for both patients and families in terms of the control of pain and other symptoms and the satisfaction expressed by patients and their families (combined odds ratio 0.38, 95% CI 0.33–0.44) (Fig. 1) (9,14).

Specialist palliative day care

There is evidence that patients value attending palliative day care units, where they can meet other patients, talk to staff and become involved in activities. There is no evidence as yet, however, that such attendance affects other outcomes such as quality or life or symptom control (9).

Bereavement support

In several studies, the relatives of patients dying in the care of specialist palliative care services reported fewer psychological symptoms and unmet needs than those of patients

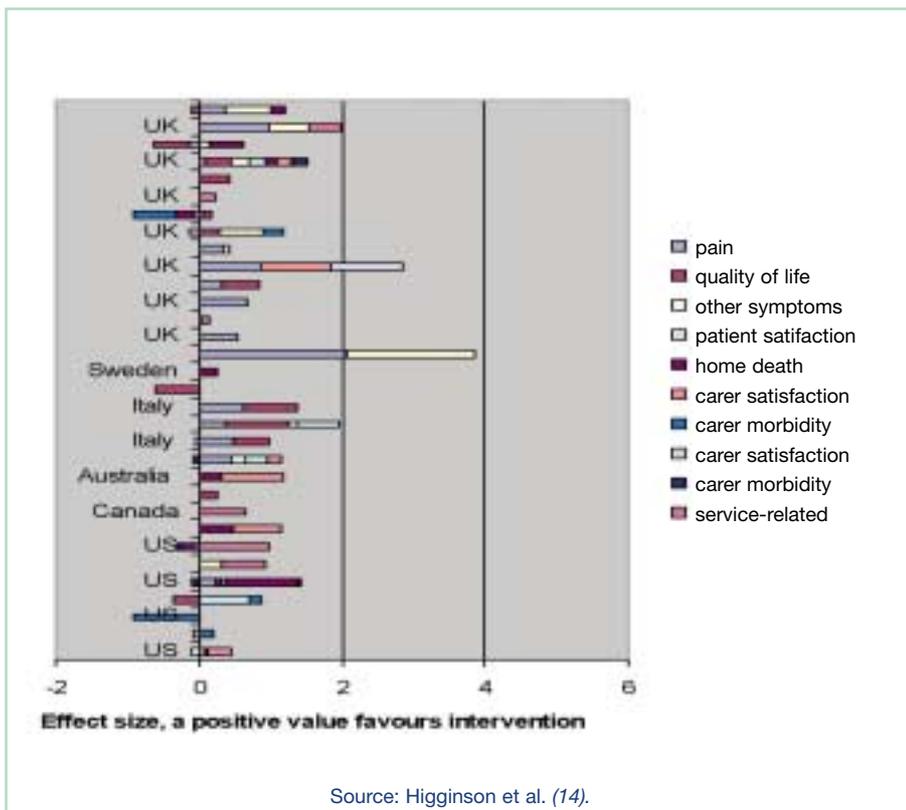


Fig. 1 - Cumulative effect size of palliative care teams, by country of study

receiving standard care (9). Assessing the need for support and counselling after bereavement is regarded as an important part of palliative care. There is relatively little evidence, however, for the predictive power of assessments, the targeting of individuals or the benefit of individual therapy, although these aspects are very difficult to evaluate (9,15).

Developing palliative care services for non-cancer patients

Multidisciplinary teams

Multidisciplinary teams are one way of caring for people with complex problems, and already have an established role in geriatric medicine and the care of people with specific disorders. For example, team management of people with cardiac failure can reduce their

hospital admissions and prolong survival (16).

Specialist nurses

On balance, studies so far show that specialist nurse support can also help patients with heart failure and improve continuity of care (17,18). Patients in the care of respiratory nurses live longer but do not have a better quality of life; they none the less place value on home visits from nurses (19).

Hospice services for patients with dementia

Pilot studies on the provision of palliative care and hospice services for patients in the end stages of dementia suggest they can make patients more comfortable and help carers (20).

Advanced care planning

There has recently been considerable interest in advanced care planning, whereby people can decide the care they would wish to have if they were to be diagnosed with a life-threatening illness. Such plans provide a written record of people's desires and preferences for health professionals and their relatives to follow if they become unable to make these decisions for themselves. Despite hopes that these might reduce the number of unwanted interventions at the very end of life, there is no evidence that such plans are always followed or that they influence the use of resources or

costs (21). More comprehensive methods are now being explored. Equally, there is little evidence for the effectiveness of intensive care in meeting the palliative care needs of older people (22).

Generalizability of findings

Research on meeting the needs of people experiencing and dying from diseases other than cancer is less well advanced. There is little specific information on effective methods for nursing or residential homes to meet palliative care needs, or of the needs of people aged over 80 in any setting. In general, there is also a lack of evidence from implementation research on how to get established evidence translated into practice. The comparatively uncertain prognoses of non-cancer illnesses make it more difficult to plan services. Nevertheless, simple measures such as good pain relief, communication, information and coordinated care from skilled professionals are effective in



reducing symptoms and suffering. It is unlikely that these experiences differ widely by disease or across countries. This strongly suggests that it is time to make a more active and concerted effort to improve palliative care, concentrating on the implementation of simple effective measures based on the complexity and seriousness of the illness and on the needs of patient and family.

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THE CHALLENGE FOR HEALTH POLICY- AND DECISION-MAKERS

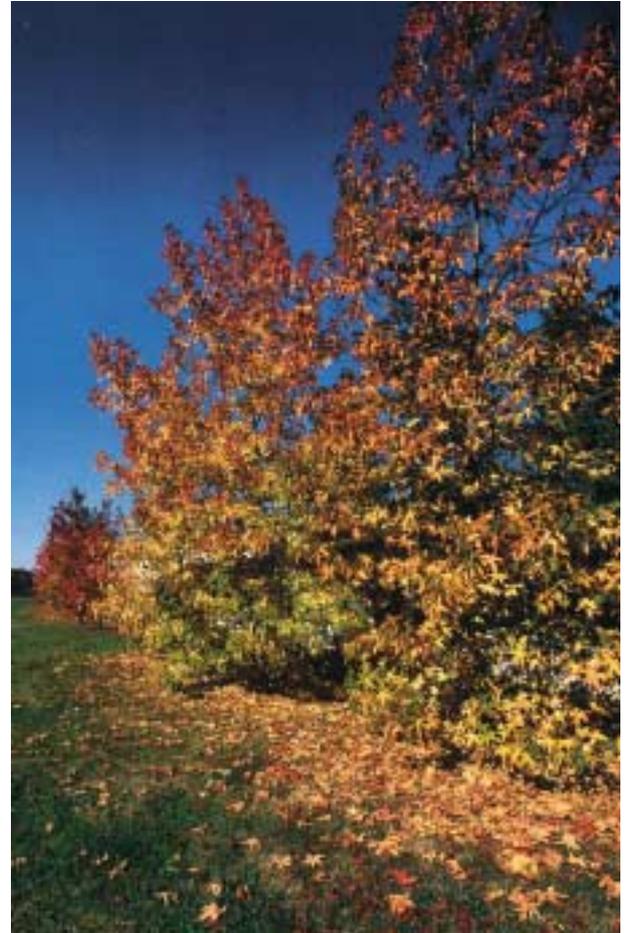
The challenge

As life expectancy increases, and more people live past the age of 65 years and into very old age, patterns of disease at the end of life are changing. More people are dying from multiple serious chronic diseases rather than acute illnesses, thus challenging health care systems to provide more effective and compassionate care during the last years of life. More people need some kind of help with problems caused by chronic heart, respiratory and cerebrovascular diseases, as well as cancer, and the population of people needing care at the end of life is now simply much older and much larger.

A considerable body of evidence shows that older people already suffer unnecessarily owing to widespread underassessment and undertreatment of their problems and a lack of access to palliative care. As a group, older people have many unmet needs, experience multiple problems and disabilities, and require more complex packages of treatment and social support. They also suffer from common serious chronic diseases other than cancer, while the predominant focus of palliative care in most countries has been on cancer.

Evidence for effective care solutions

Reviews of evidence from many countries show the importance of core aspects of palliative care for cancer patients and the effectiveness of simple measures in improving patient outcomes. These include adequate pain and symptom relief, good communication and information, and coordinated care from teams of skilled professionals who help meet preferences for care. Although the comparatively uncertain prognoses of other illnesses may make it more difficult to plan services based



on prognosis, patients experiencing non-cancer illnesses have similar needs and will benefit equally from the same measures. This suggests that it is time to make a more active and concerted effort to improve care, by concentrating on simple proven measures based on patient and family needs and the complexity and seriousness of the illness.

Barriers to overcome

The growth of the hospice and palliative care movement over the last 30 years has demon-

strated the effectiveness of palliative care in improving care towards the end of life. The development of special expertise in caring for people with cancer and their families is endorsed by the public support of its work. A substantial body of opinion recognizes that this model of care now needs to be adapted for other patients on the basis of need rather than diagnosis or prognosis.

However, it takes more than knowledge and good will or good intentions to translate this into action. Achieving better palliative care for older people requires a willingness to listen to them and their families, imagination, and a determination to remove barriers at all levels of health care systems. These barriers include:

- a lack of awareness and knowledge of the scale of the problem;
- a lack of health policies for palliative care, both for older people and for the diseases they commonly suffer from;
- a lack of integration of palliative care across health care settings and services;
- a lack of palliative care ethos or skills in the settings where older people are actually cared for and die;
- complacency and age discrimination about the need to provide high-quality, end-of-life care for older people;
- faulty assumptions about the needs of older people and their desire or ability to cope without special forms of help;
- failure to implement simple proven effective measures;
- the complexity of linking care packages across different settings and between health and social support and care; and
- a lack of resources and outdated patterns of care and health systems delivery.

Potential solutions: a public health policy approach

The scale of the need for palliative care for the growing population of older adults suggests that it requires a multifaceted approach and the application of public health methods to make an impact. This means identifying needs within populations, monitoring trends and the effectiveness of interventions, increasing professional education and public awareness, and setting up systems that can support the changes needed in behaviour and practice.

Palliative care for older people must be included within health service planning at a national level. Each country must decide how much priority and resources to give to this area, but it must be defined clearly. There is evidence, for example, that funding hospices in the United States has led to financial stability, thus encouraging long-term planning including care for non-cancer patients. Policies for palliative care need to be linked to other health care policies for older people, and to specific diseases such as heart disease and dementia.

Ensuring palliative care is integral to health services

Policy-makers need to ensure that palliative care is integral to the work of all health services and is not seen as just an “add-on extra”. This involves promoting effective care, monitoring, and rewarding health organizations for improving quality. Effective palliative care for older people also requires partnerships between geriatric medical teams, nursing homes and palliative care staff. The challenge of integrat-

ing palliative care more fully across all settings and health services is already being met in some countries. The Netherlands health policy for palliative care, for example, provides some examples of care from which others could learn, and suggests that change is possible. Current variation within countries also suggests that change is possible. A range of quality improvement methods has been developed to improve palliative care and these are currently being tested in different settings. In the United Kingdom, for example, national audits of the care of hospital patients with stroke have already resulted in wide-ranging improvements in care. Exciting preliminary results are emerging from using continuous quality improvement methods in the United States. Some reliable instruments, including the Support Team Assessment Schedule (STAS), The Resident Assessment Instrument (RAI) and the Comprehensive Geriatric Assessment (CGA) have been developed. Other methods being developed include routinely collecting information from bereaved relatives and feeding this back into care planning.

Improving the application of palliative care skills across all settings

Much of the suffering of older people could be alleviated if currently available treatments were used more widely. One problem seems to be lack of training in pain and symptom control, and a reluctance to use opioid drugs in primary and secondary care outside specialist settings. Tackling this will involve expanding education and training for staff providing care in all settings, including residential and nursing homes as well as hospitals and the patient's own home.

Identifying gaps in the research base

Needs during the last years of life have not been a research priority so far, and in general



much more money is spent on research into potentially curative treatment. This means that the evidence base for palliative care is incomplete. In the United Kingdom, for example, only 0.18% of the cancer research budget is spent on palliative care or end-of-life research. In general, there is more research available describing the needs of people towards the end of life, and interventions that might provide a potential solution, as opposed to formal evaluations of their effectiveness. Randomized controlled trials, often seen as the gold standard of research, are much more difficult to undertake among such vulnerable populations.

Another difficulty is that many of the most effective interventions involve changing the behaviour of health professionals and the organization of their work. This barrier to the implementation of proven effective methods applies to all health care, but is particularly formidable in the effort to extend palliative care to older people with serious chronic illness. This makes the field more complex than those in which single effective technologies may be introduced. Research and development urgently needs to tackle the complexities of implementing improvements in this area.

RECOMMENDATIONS

Policy- and decision-makers need to:

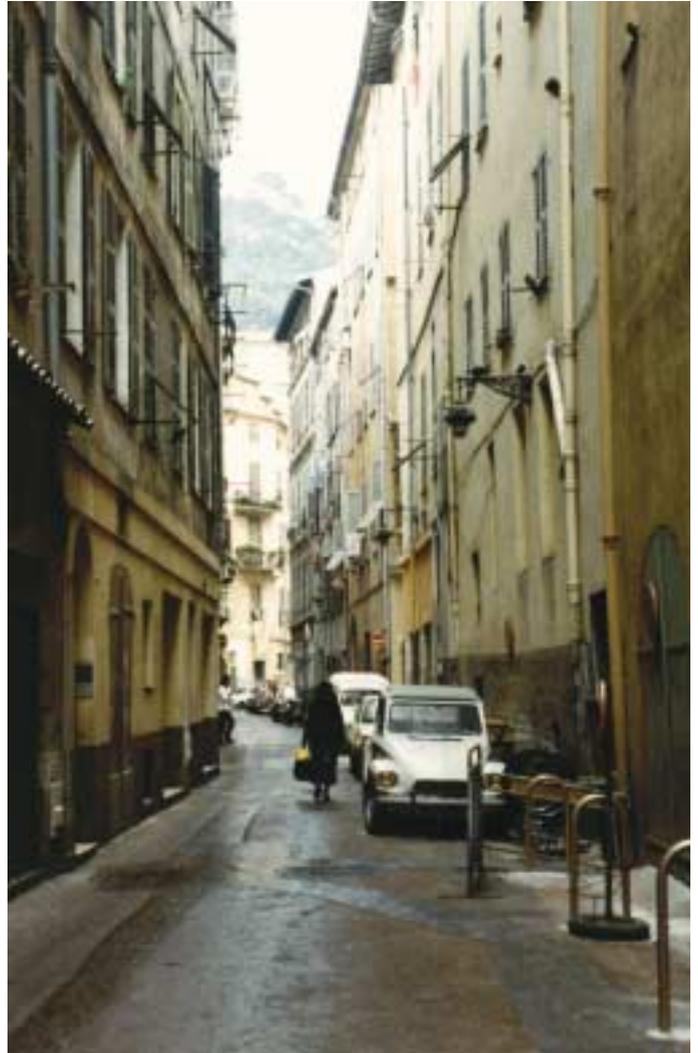
1. recognize the public health implications of ageing populations with palliative care needs, and that substandard care towards the end of life is a public health problem;
2. undertake, at national or regional population level, a “quality audit” of palliative care services delivered to older people in nursing and residential homes, hospitals, hospices and at home, including staff qualifications in these institutions, and define a method to “track” improvements in care;
3. invest in the development of small core data sets that link different care settings locally, and that can be used to identify and monitor the needs of older people;
4. invest in audit and quality improvement methods to improve the care provided for local populations, and reward the involvement of health organizations, including nursing homes, in audit and quality improvement schemes;
5. ensure that multidisciplinary services shown to meet the needs of older people for palliative care are adequately funded, rewarded and supported;
6. ensure that the training of health care professionals includes sufficient time devoted to palliative medicine and the care of older people, and that professionals are supported to keep up to date;
7. demand and invest in high standards in palliative care for older people, including pain and symptom management, communication skills and coordination of care;
8. act against ageist stereotypes that affect whether older people are offered palliative care when they need it;
9. involve older people – as the users of services – in making decisions about the types and mix of services they want available to them towards the end of life and into bereavement; and
10. provide information about the range of services available, including for symptom control, and their effectiveness for older people who are facing life-threatening, chronic or progressive illness.

Health professionals need to:

1. ensure they are adequately trained in the palliative care of older people, including pain and symptom management, communication skills and care coordination;
2. ensure that older people with palliative care needs are regarded as individuals, that their right to make decisions about their health and social care is respected, and that they receive the unbiased information they need without experiencing discrimination because of their age; and
3. ensure that their organizations work in a coordinated fashion with other statutory, private or voluntary organizations that may help older people needing palliative care.

Those funding research need to:

1. invest in research into the geographical variation between and within countries in the palliative care that older people receive;
2. invest in creative research into the barriers to accessing palliative care, the etiology and management of non-cancer pain and other symptoms in older people, their subjective experience of care, the psychological and social needs of different cultural groups, the testing of advance care planning that promotes patient-directed care, and meeting the needs of frail older people;
3. promote collaboration in research between palliative and geriatric medicine in the areas of palliative care, and the inclusion of older people in all kinds of innovative research on physical interventions, including drug treatment;
4. invest in research into effective palliative care and treatment for older people across a range of conditions, making this a significant component of research investment;
5. promote the development of standardized assessment tools for palliative care in older people, and how these and methods such as “report cards” might be meaningfully used across different countries; and
6. ensure that research in care and treatment does not exclude older people.



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The Floriani Foundation was established in 1977 with a donation from Virgilio and Loredana Floriani, and was the first in Italy to set up free home care for terminally ill patients. The aim of the Foundation is the dissemination and application of palliative care to assist terminally ill patients, care that takes account of all aspects of the patient's suffering: physical, psychological and social. The Foundation's other concept is that patients and their families are followed at every step along the final difficult journey.

With the aim of spreading the application of palliative care in Italy and throughout the world, the Floriani Foundation has promoted and supported the setting up of the European Association for Palliative Care, the Italian Association for Palliative Care and the Italian School of Palliative Care.

The Floriani Foundation also founded the Association of Friends of the Floriani Foundation, whose purpose is, in addition to promoting and organizing events, to raise funds and carry out the aims of the Foundation.





The European
Association of
Palliative Care



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