WORLD HEALTH ORGANIZATION
EUROPE

THE SOLID FACTS

PALLIATIVE CARE

Edited by
Elizabeth Davies and Irene J Higginson

Supported by the Floriani Foundation

With the collaboration of:

The European Association of Palliative Care

OPEN SOCIETY INSTITUTE
The Open Society Institute Network Public Health Programme

King's College London

The European Institute of Oncology

KEYWORDS

END OF LIFE CARE
DEATH AND DYING
PALLIATIVE CARE
PUBLIC HEALTH
LIFE-THREATENING ILLNESS
SERIOUS CHRONIC ILLNESS
SUPPORTIVE CARE
TERMINAL CARE

ISBN 92 890 1091 6

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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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Foreword

Palliative care is an important public health issue. It is concerned with the suffering, the dignity, the care needs and the quality of life of people at the end of their lives. It is also concerned with the care and support of their families and friends. This is by and large a neglected topic in Europe, but is one that is relevant to everybody in the Region.

The purpose of this booklet is to provide a concise overview of the best available evidence on the concept of palliative care and of related services. It is written mainly for decision-makers and health professionals at all levels. Translating scientific evidence into policy and action is a complex process. We hope the booklet will be used as a tool for spreading awareness and for stimulating debate and, above all, policy development and action.

The booklet is the result of a systematic and comprehensive effort to review scientific evidence and to make policy recommendations, drawing on the expertise, suggestions and inputs of individuals from many academic centres and disciplines. It expresses a European viewpoint, but may nevertheless reflect issues relevant to other parts of the world. During the review it has become clear that the evidence available on palliative care is not complete, and that there are differences in what can be offered across the European Region. Issues for further work have been highlighted.

The booklet is linked to another publication entitled *Better palliative care for older people.* The two booklets are independent but interconnected. The former sets the scene of the multiple facets of palliative care and the latter considers the care of older people in more detail. The job of policy-makers can be greatly helped by access to clear scientific facts, good arguments, guidance and lessons that are based on real experience and legitimacy. I am convinced that both of these timely publications live up to these qualities.

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.

Dr Agis D. Tsouros
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Preface

Palliative care begins from the understanding that every patient has his or her own story, relationships and culture, and is worthy of respect as a unique individual. This respect includes giving the best available medical care and making the advances of recent decades fully available, so that all have the best chance of using their time well.

Originating in small hospice teams, the proliferation of palliative care developments worldwide illustrates the truth of the saying attributed to the noted anthropologist Margaret Mead: “Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it’s the only thing that ever does”. The time has now come for the next stage – a public health commitment drawing on this extensive experience.

One powerful element of the work that developed into the whole spectrum of palliative care was a breakthrough in the attitude to pain, as it became recognized in all its complexity in the 1960s. It began with a concentration on cancer pain. This focus made possible the early research that led to the booklet *Cancer pain relief*, published by WHO in 1986. Palliative care has now, as originally envisaged, spread to concern for the often complicated pain suffered by people with other life-threatening diseases.

The next stage is surely the introduction of palliative care into mainstream medicine and a determined programme of both professional and public education. This aim is to give not only relief but also the possibility of choice to each individual and family, a possibility often sadly lacking at present. The family, itself the main caring team in the community, needs the advice of a multidisciplinary group of professionals if it is to reach its own potential for enabling patients to live as fully as possible to the end of their lives. Sound memories will then enable the bereaved to experience a satisfaction that helps them live on.

This requires both a social and a political impetus, entailing changes in attitudes and widespread education of all professionals involved with patients who have a life-threatening illness. It demands human commitment rather than expensive drugs and interventions, and should be a concern for all governments.

This booklet presents these challenges with exemplary clarity.

Dame Cicely Saunders

INTRODUCTION

Overall life expectancy is increasing in European and other developed countries, with more and more people living beyond 65 years of age. As part of population ageing, the pattern of diseases people suffer and die from is also changing. The last century saw a dramatic reduction in deaths from infectious diseases in infancy and childhood. Increasingly, people die at older ages following illnesses due to serious chronic conditions, which cause a wide range of physical, psychological and social problems. Health care systems must be able to meet the needs of these people by reducing suffering and supporting people of all ages to live well and maintain their quality of life for as long as possible.

As people come closer to death their symptoms change rapidly, and their need to communicate with their families, friends and health professionals also changes. Coming to the end of life is an intensely personal event that can be

emotionally and physically demanding. Patients and their families often need particularly responsive kinds of help during this phase, and health care must be tailored in a way that allows a rapid response as people's needs increase. This includes ensuring good pain and symptom control, comfort, sensitive communication, clear information and a coherent package of care. These measures can help people live meaningfully until the end of life and support their families afterwards.

We all die, and although this reality is as much a part of life as birth, thinking about it is not easy. Individually we may plan the treatment we would wish to have towards the end of life, or anticipate the comfort we might find in cultural and religious beliefs, but most of the time we choose to avoid thinking too much about it. Health care systems, however, do not have the option of prevarication. Many people already need better care towards the end of life. As well as providing this, health care systems must plan now for the care we will all need in the future.

Traditionally, palliative care has centred on the needs of patients and their families at the end of life, but it has mostly been offered to cancer patients. Emerging needs of people living with serious chronic illnesses, together with new evidence for the effectiveness of palliative care, mean it must now be offered more widely and integrated more broadly across the health care services. The relative neglect of palliative care in health policy presents urgent public health challenges for health policy- and decision-makers. This booklet recommends key areas that they need to consider. It takes a public health approach, addressing information on epidemiology, trends, staffing issues, quality improvement methods and community responses that will help plan for care towards the end of life.

Drawing mainly on evidence from Europe and North America, this booklet discusses ten different aspects of palliative care:

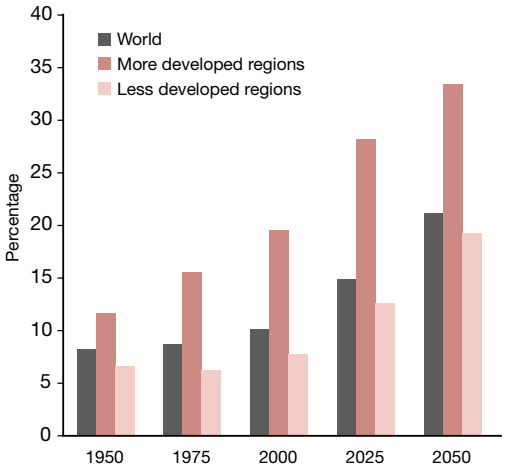
1. why changes in populations make care towards the end of life a public health issue;
2. the emerging needs for care;
3. what palliative care is;
4. the importance of individual rights, preferences and options;
5. the evidence for effective palliative care;
6. the need to ensure access to palliative care for vulnerable groups;
7. how to develop programmes to improve the quality of palliative care;
8. how to improve education and training in palliative care for health professionals;
9. the need to increase public awareness of palliative care issues and options; and
10. the kinds of research and development on palliative care that will help policy-makers.

Population ageing and the implications these present for care towards the end of life are major public health issues for the 21st century

The evidence

Population ageing

Populations in European and other developed countries are ageing (Fig. 1). People are living longer and the proportion of those living beyond 65 years and into very old age is increasing.



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

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

The changing pattern of disease

In line with the ageing of the population, the pattern of diseases that people suffer and die from is also changing. Increasingly, more people die as a result of serious chronic disease, and older people in particular are more likely to suffer from multi-organ failure towards the end of life. The top five predicted causes of death for 2020 are heart disease, cerebrovascular disease, chronic respiratory disease, respiratory infections and lung cancer (Table 1).

It is not yet entirely clear whether increased longevity is inevitably accompanied by longer periods of disability towards the end of life. Some recent findings and predictions suggest an optimistic picture, with disability declining in successive cohorts of people as they age. 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.

Table 1 - 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 *(2).*

This means that there will be more people needing some form of help towards the end of life.

The changing social structure

At the same time, the numbers of informal caregivers – particularly women, who have traditionally been relied on to care and support people towards the end of life – will be decreasing. Families have become smaller, more dispersed and varied, affected by increased migration, divorce and external pressures. Fewer women (and men) will be able to find the time to provide support and care. Health care systems will therefore find themselves challenged to provide effective and compassionate care for larger numbers of people at the end of life.

This change in the structure of the population does not necessarily mean that the cost of care for people in the last years of their life will eventually overwhelm health service funding. In fact, international comparisons show no consistent relationship between the proportion of older people and a country's total health care costs. However, innovative ways of providing care can be developed to meet needs. There are already examples of excellent practice, based on collaboration between enthusiastic health care professionals in different countries. The key task for health planners and policy-makers is to begin to use this information to plan effectively for the needs that we will all have towards the end of our lives.

Policy implications

1. Policy-makers must begin to plan now to meet the needs of ageing populations for care towards the end of life.
2. Health care systems must place much greater emphasis on the care of people of all ages who are living with and dying from a range of serious chronic diseases.

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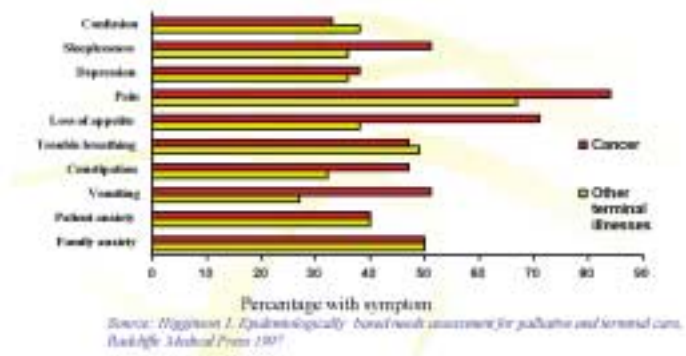
People living with different serious chronic illnesses often have similar concerns and needs

The evidence

The range of problems for different illnesses

People living with serious chronic diseases face a wide range of problems and each illness brings specific symptoms. Ischaemic heart disease may cause the chest pain of angina, or the breathlessness and fatigue of heart failure. Stroke due to cerebrovascular disease may cause difficulty in moving or talking, while chronic obstructive pulmonary disease may restrict activity because of breathlessness. Chronic diseases often come together and so add up to cause many problems affecting the quality of people's lives. HIV infection and AIDS have a relapsing and remitting course, and often produce multiple symptoms and problems that require alleviation. Although survival is much improved for many, it is still very poor in some countries and for some sections of society.



Source: Higginson *(1)*.

Fig. 2 - *Prevalence of problems in the last year of life*

Although there are some differences between individual diseases, epidemiological studies show that many symptoms and problems in the last year of life are similar (Fig. 2). The intensity of these symptoms may vary and this needs further study.

The concerns and needs of patients and families

Concerns and the interpretation of terms such as "quality of life" are highly individual. Some people are most concerned about physical symptoms such as pain, and some by the effect the illness has on their everyday life. Others may be distressed by the uncertainty of their situation, by religious or spiritual concerns, or by the effect of their illness on their family. Patients' views can be different from those of their health professionals, and different in turn from those of the family members caring for them.

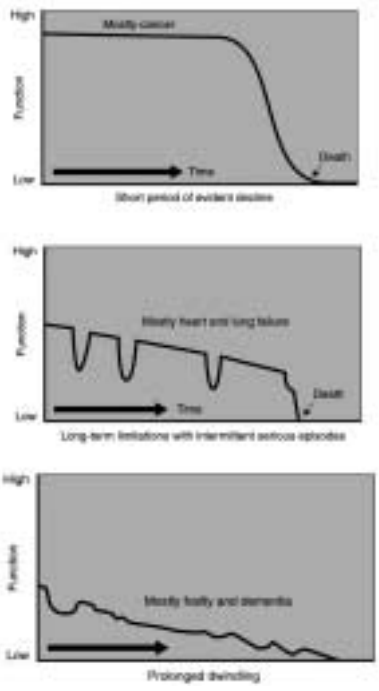
Most research so far has concentrated on people living with cancer. Concerns common to many include the need to communicate with their family members and health professionals, and to cope with disability, pain, anxiety and depression. Family members and caregivers often report needing support in caring for the ill person, and in coping with anxiety and depression. The latest research findings now show comparable concerns and possibly greater needs at some points in the illness for those experiencing non-cancer illnesses.

Needs caused by the uncertainty of the prognosis

Although the course of an illness due to cancer can often be predicted, there is uncertainty for many other common chronic diseases (Fig. 3).

People with heart failure or chronic obstructive respiratory disease, for example, may live with more disability for longer, but die suddenly with little warning after a rapid deterioration. People with dementia may live for a long time but become increasingly dependent yet unaware of those close to them, which can be particularly distressing for their families. This is considered in more detail in the accompanying booklet, *Better palliative care for older people.*

The trajectories of common serious illnesses other than cancer can give the impression that they will be more difficult to plan services around. However, uncertainty of prognosis does not mean that the needs of these patients and their families are any less important.



Source: Lynn & Adamson *(2)*.

Fig. 3 - *Models of the illness trajectory for common serious chronic diseases*

Policy implications

1. Policy-makers must invest in providing publicly funded palliative care services as a core part of health care and not as an "add-on extra".
2. Policy-makers must take steps at a population level to ensure that unmet needs for care are identified for all common serious diseases, including cancer, ischaemic heart disease, cerebrovascular disease, chronic obstructive respiratory disease, end-stage liver and kidney disease, infectious diseases and dementia.
3. Policies need to identify people living with serious chronic illnesses in widely different settings such as the community, nursing homes and hospitals, including intensive care.
4. Policies must also recognize the work of families and caregivers and support them to help care for the patient and to cope with the sense of loss that the illness brings. This might include assistance similar to that often granted to those with maternity and paternity responsibilities.

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Policies for palliative care need to be developed as part of an innovative global public health policy

What is 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 problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

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.

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 importance of recognizing "total pain" and wider needs outside of the cancer field

Patients attempting to describe pain use such phrases as "it seems as if all of me was wrong" and speak not only of [pain and] other symptoms, but also include descriptions of their mental distress and their social and spiritual problems.

The lessons learnt so far in the now world-wide field of palliative care were never meant to be confined to one group of patients and their families. Carers struggling to cope over long periods of stress are equally deserving of support and their voices are too often unheard.

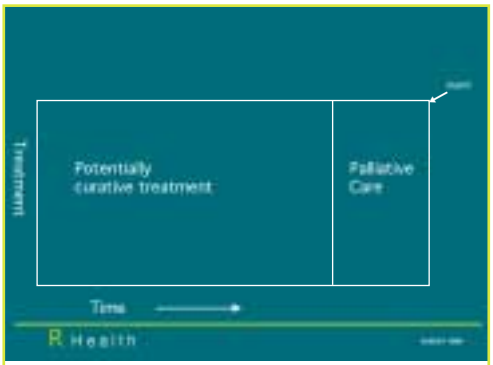
Dame Cicely Saunders, Founder of the modern hospice movement, 1964 and 2001.

But isn't this just good health care?

All areas of health care that provide holistic care for people with chronic illness have for many years recognized the wider needs of patients and their families. This is especially true for general practice, geriatric medicine, paediatrics, psychiatry and rehabilitation. Palliative care has focused on controlling pain and other symptoms, defining needs around patients and their families, and being flexible about doing what is necessary to help people adapt and cope with their situation.

What new needs to be done?

As ageing populations develop new needs, health care systems need to be equally flexible in their response, and perceptions about care towards the end of life need to change. Traditionally palliative care has been offered most often to



Source: Adapted from Lynn & Adamson *(2)*.

Fig. 4 - *Traditional concept of palliative care*

people suffering from cancer, partly because the course of this illness has been more predictable making it 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 – when no other treatments are beneficial – and can be delivered only by specialized services (Fig. 4). 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 concept of offering palliative care only at the end of life clearly not does fit many common situations, whereby people need palliative care after diagnosis and continue to benefit from treatments that alter the progress of disease until the end of life. New concepts of palliative care try to match the service more closely to what is understood about the course of the illness (Fig. 5).

Source: Adapted from Lynn & Adamson *(2)*.

Fig. 5 - *New concept of palliative care*

The concept of palliative care as an intervention that can be offered alongside potentially curative treatment must be developed and used to meet the needs of ageing populations, as well as those of younger people and children who experience life-threatening illness.

Policy implications

1. These concepts of palliative care must be developed and used to meet the needs of ageing populations as well as those of younger people and children who suffer life-threatening illness.
2. Services for palliative care must be offered more widely, and broadly integrated across all health services.
3. Services should be available on the basis of need in terms of symptoms and problems, and their effectiveness in meeting that need, rather than on the basis of diagnosis.

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Good quality care towards the end of life must be recognized as a basic human right

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

Ethical arguments

All people have a right to receive high-quality care during serious illness and to a dignified death free of overwhelming pain and in line with their spiritual and religious needs. Although palliative care originally developed for people with cancer, ethical concerns about fairness, equality and equity require that this standard of care be offered to other people with similar needs. There are also important ethical concerns about how care should be offered and the choices people may wish to make about this.

People who are very sick or are coping with serious chronic illness have their own experiences and values. People vary greatly in their willingness and ability to talk openly about their illness or its prognosis, the needs they wish to acknowledge, the level of symptom control they find acceptable, the interventions they will consider, and whom they wish to care for them. Taking account of these values is one important way in which health professionals can help individuals and their families feel they are in control. Enabling people to become involved in decision-making requires sensitivity to personal and cultural values, empathy and an ability to inform and empower people to make choices about their care when they wish.

The evidence

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).

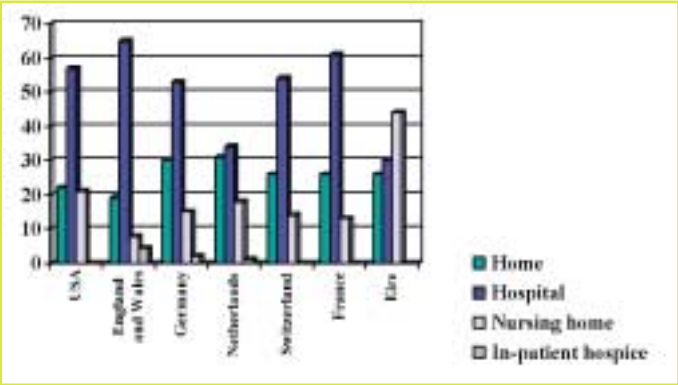

Fig. 6 - *Preliminary data on place of death by country*

Sources: United States: Weizen SMS et al. *(1)*; 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. Germany: Thomas Schindler, personal communication. Ireland: Julie Ling, 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.

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. 6). Detailed work in the United States, for example, has found variation in the proportion of people dying at home ranging from 18% to 32%. The Netherlands has reported some success in providing a range of palliative care services in different settings and in allowing people to die at home if they so wish. In many countries the number of deaths occurring in nursing homes is also increasing.

Policy implications

Some countries are now developing national and regional palliative care strategies, and each country needs to decide which options for care are priorities and can be offered or planned for. However, if people do not receive information on what care is available, it is difficult to argue that the best care has been offered. Currently, most health care systems are not set up in a way that makes it easy for people to receive palliative care or to die where they would wish. In many countries data on place of death are not collected nationally.

1. Public health policy must acknowledge people's right to high-quality palliative care and to make decisions about it, whatever the nature of the disease they suffer from. These rights should be enshrined in health and social care legislation.
2. Policy-makers should monitor the wishes of seriously ill people concerning place of care and death.
3. Policy-makers should routinely monitor place of death as one interim measure of success of the system of palliative care provided.
4. Policy-makers should encourage the health services to inquire of people their preference for place of care and death. Meeting individual preferences should be the ultimate measure of success.

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Simple measures, including pain relief, sensitive communication and well coordinated care, are effective in relieving symptoms and suffering

The evidence

Pain and symptom control

Palliative care has developed expertise in pain and symptom control over many years. Most of the pain experienced by people with advanced cancer can be controlled if appropriate clinical guidelines are followed and effective drugs, including opioids, are available. Palliative care has promoted wider application of the principles of pain and symptom control. However, more work is needed to train all professionals in assessing, monitoring and treating pain and distressing symptoms in all settings.

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. 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. The communication skills of health professionals can be improved by using feedback from videotaped consultations and discussion, but they still need further help to sustain these new skills in everyday practice.

Giving information

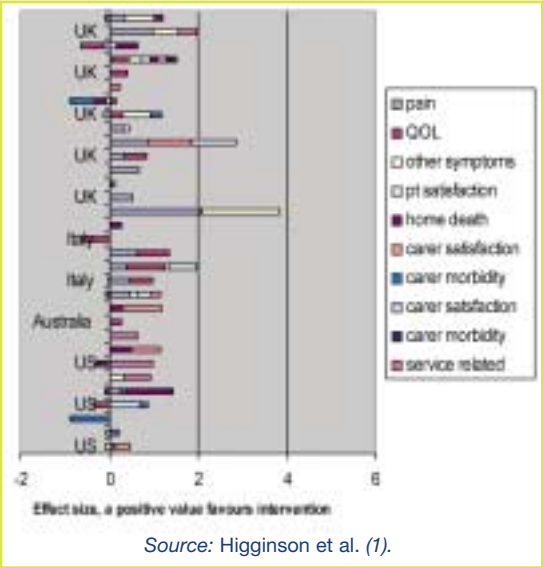
Recordings or summaries of key consultations are of benefit to most cancer patients. They lead to improved knowledge and recall of information without causing psychological problems as well as greater satisfaction. Nevertheless, these must be used sensitively with patients whose prognosis is poor, and account must be taken of whether or not they wish to know the full facts.

Support for family and caregivers

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.

Coordinated services

The organization and delivery of palliative care services varies in different countries, depending on historical norms and national policies and patterns of funding. In many countries, health professionals in primary care and hospitals carry out much palliative care. Some countries have focused on developing inpatient palliative and hospice services. In others, there has been a greater emphasis on home care, on sharing care with other teams or on hospital support. In some instances, hospices or palliative services take complete responsibility for care.



Source: Higginson et al. *(1).*

Fig. 7 - *Cumulative effect size of palliative care teams, by country of study*

However, almost every study uncovers the importance that patients and families place on receiving a well organized package of care. Trials on different ways of coordinating services, often through palliative care services, across the different settings of hospital, home and community are now finding that a higher proportion of people can be helped to remain and die at home if they wish. There is also evidence that this coordinated palliative support can improve the quality of life of family and carers.

Specialist palliative care services

As palliative care has developed, a common model of providing care has been to concentrate expertise in multiprofessional teams who work within hospitals, inpatient units, hospitals or the community. The role of these teams is to assess the patients' symptoms and problems and devise ways of improving these and of providing more general support for patients and their families. These teams therefore usually deal with a selected group of patients, who have the most complex needs for symptom control, communication and coordination of care, referred to them by other teams of professionals. Despite this, the evidence on the effectiveness of specialist palliative care teams consistently adds up to benefits for patients and families, as measured by the control of pain and other symptoms and the satisfaction expressed by patients and their families (Fig. 7). These teams may also encourage improvements in symptom management and communication among local nonspecialist services through education and liaison.

Policy implications

1. Policy-makers need to promote the development of palliative care skills in staff working across all settings, especially in pain and symptom control and communication.
2. Palliative care services must be coordinated across different settings of home, hospital, inpatient hospice, nursing home and other institutions.
3. Policy-makers need to invest in the funding of the full range of effective palliative care services, including specialist teams to ensure that patients and their families have access to the services they need.

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Some vulnerable groups within society have unmet needs and equal access to good quality palliative care must be ensured

The evidence

Despite progress in developing palliative care, in several countries there is evidence that some groups in society are excluded from the best of these services, or have special needs that are not well met. These can include the less affluent, members of some ethnic minority groups, older people and children.

The reasons for variations in access are unclear. They may reflect untested assumptions about the desire and ability of different groups to cope without the special form of help available, discrimination, lack of skills in detecting concerns, or more general problems with the way that health care is structured.

Socioeconomic status

People living in less affluent areas have higher death rates from some cancers, but are more likely to die in hospital and less likely to die at home. These findings, first reported in the United Kingdom and replicated now in Italy, suggest that it may be more difficult to provide home care services in deprived areas. Other groups that are hard to reach include homeless people, prisoners, travellers, long-term psychiatric patients and those with learning disabilities.

Cultural and ethnic groups

People of all backgrounds and beliefs may experience spiritual pain and existential crises towards the end of life. Health care staff need to be able to recognize such crises and be aware of how to seek help from representatives of the range of faiths and beliefs in society. In the United Kingdom, people from some cultural and ethnic groups are less commonly cared for in inpatient hospices. There is evidence that their needs for

pain control are not fully met and that health professionals need to be more aware of the cultural diversity within societies today. The level of autonomy desired, the wish to know the truth, and the way in which death is viewed and the rituals that accompany it vary widely between and within cultural groups.

Older people

Older people do not have access to hospice and palliative care services in the proportions that might be expected. There is considerable evidence of under-assessment and undertreatment of symptoms such as pain in hospitals and nursing homes, which are the setting for much care that is provided to older people in the last years and months of life.

Children and adolescents

Children and adolescents are a special group, as their death has a devastating and enduring impact on families. The palliative care team will play a central role, seeking to prevent unnecessary suffering, communicate sensitively and avoid future regret for parents over the choice of treatment, which can in itself cause suffering. Care often needs to be provided in a range of settings, including the home and inpatient and respite care.

Policy implications

As for all other areas of health care, there is a constant need to ensure that access is equitable for all members of society. Ensuring equitable access to palliative care is at least as important as access to any other kind of health care. This is an underresearched area, where there are many gaps in our knowledge, and where multinational comparison might be valuable.

1. Health policy-makers need to ensure that national systems are in place to monitor access to palliative care for all groups in society.
2. Health care organizations need to invest in local systems for identifying vulnerable groups, and for monitoring and improving the quality of services provided to these populations.
3. Policy-makers need to promote the dissemination of good practice in reaching vulnerable groups.

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Many innovative ways of improving the quality of care towards the end of life are being developed and must be shared across teams, organizations and countries

There is already much that we know, particularly in the area of symptom management, that would improve care if we applied it more effectively in practice

The evidence

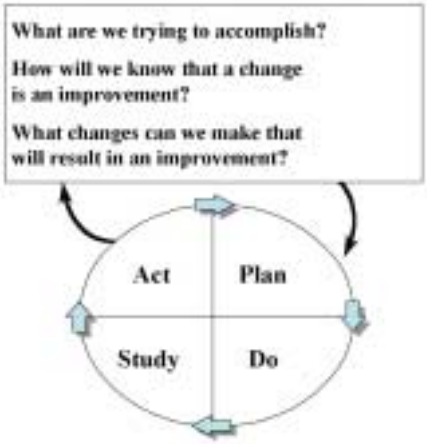
Knowledge is not enough

It is increasingly clear that new knowledge about effective care rarely leads to widespread improvement without a deliberate effort being made to change practice. Many countries are therefore attempting to develop more systematic ways of using knowledge to improve their health services. These methods include developing clinical guidelines and audit, developing care pathways, involving users of services in designing change and seeking their feedback more regularly, and devising methods that encourage teams of professionals to work together to improve the quality of the services provided.

Changing organization, practice and behaviour, however, is not easy or simple. In the cancer field, for example, developing evidence-based clinical guidelines for health professionals has met with mixed success. Reviews of these initiatives suggest that guidelines need to be locally developed and championed, and supported by education, feedback, multiprofessional collaboration and effective project management. Some specific audit tools have also been developed for palliative care to measure important outcomes, and have been used successfully in different settings.

Promoting innovative approaches

Actively involving people who are receiving palliative care in the design of services can be more difficult than in other areas of health care, because of the need to avoid overburdening severely ill patients. It is not impossible, however, and some projects are developing flexible models in this area. Other approaches include regular surveys of



Source: Langleg et al. *(1).*

Fig. 8 - *A model for improvement*

patients receiving care, or surveys of bereaved relatives for their views on the quality of care the patient received. These results can be fed into local needs assessments and thus influence the planning of services. One method currently attracting interest is continuous quality improvement. This can be implemented in one service or can be organized so that many teams meet within a "collaborative". Either way, the teams providing care learn how well their local system is working, measure what happens within it, and attempt to change it in a repeated cycle of planning, implementation, insight and planning again (Fig. 8). Exciting reports are emerging of success in applying this technique locally. Local palliative care networks might be useful in sharing good practice among health care organizations.

Policy implications

It is unlikely that any one of these new methods for improving quality will work well across all situations or be sustained without effective leadership, staff involvement and funding (2). Change of this kind does not occur rapidly and it may take several years for knowledge to be assimilated, new skills and practice to be learnt and accepted, and supporting structures and networks to evolve. Investment in improving services therefore needs to take a long-term view.

1. Policy-and decision-makers should reward health care organizations that engage in audit and quality improvement schemes in palliative care.
2. Policy-makers should encourage the dissemination of examples of good practice and constantly review the success of these methods in palliative care.
3. Health care organizations need to develop and maintain cultures that support health professionals to work well in teams and to identify areas of palliative care that might be developed or improved.
4. Demonstrations of innovative approaches and evaluation of their merit in palliative care need to be widespread and encouraged.

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Health professionals need to be trained well in palliative care, to have opportunities to extend their knowledge, and to work within organizations that promote attitudes and behaviours to sustain these skills

The evidence

Traditional education

Although this is slowly changing, palliative care has traditionally not had a high profile within the general education and training of health professionals. Many medical and nursing textbooks often have virtually no information on care towards the end of life, apart from on prognosis (Fig. 9). This may explain why health professionals often report that they do not feel well trained in the areas of breaking bad news, assessing prognosis, controlling symptoms or helping patients with difficult decisions. It may also partly explain why people are often referred too late or not at all for palliative care. Nevertheless, there is encouraging evidence that many of these skills can be acquired during undergraduate and postgraduate training and later.

Aspect	Cause of death			
	Lung cancer	Stroke	Dementia	Chronic Obstructive Pulmonary Disease
Prognosis	✔✔✔	✔✔✔	✔	✔✔
Symptons	✔		✔	
Mode of death			✔	✔
Decision making			✔	
Effect on family			✔✔	

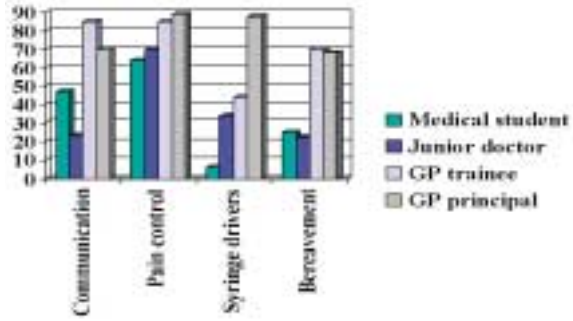
Source: Adapted from Carron, Lynn & Keaney *(1).*

Fig. 9 - *Information on end-of-life care for four major causes of death contained in four American medical textbooks*

Learning in everyday practice

Studies of medical students find that those given the opportunity to follow people with cancer for longer periods of time, or to learn from them in communication skills training, are more knowledgeable and willing to listen, discuss difficult topics and help people make decisions. There is also evidence that fully qualified nurses and doctors can acquire further skills in communication by attending intensive courses later in their training and careers. However, it is not always easy for these professionals to sustain new skills given the reality of everyday practice. This may mean that professionals need more training with constructive feedback over longer periods of time, or that health care organizations need to do more to develop cultures and working practices in which such skills can be used (Fig. 10). This includes making extra time available to deliver high-quality care and ensuring that facilities are suitable. Even the most highly trained professionals find it difficult to work at their best when they feel hard-pressed, hurried, unvalued and vulnerable to criticism.

Ethical issues in the care of patients are increasingly complex, particularly in progressive and serious illness. Training and debate on ethical aspects on a range of issues are thus essential. These include



Source: Barclay et al. *(2).*

Fig. 10 - *Percentages of doctors at different career stage receiving training in aspects of palliative care*

confidentiality, discussing the prognosis and the benefits and burdens of treatment, working with complex patient and family dynamics, advanced directives, resource allocation, assessing and talking with patients and families who request assisted suicide or euthanasia, withholding and withdrawing treatment, and making decisions on behalf of patients who are unable to communicate.

Training all professionals

It is unrealistic to expect the wider emerging needs for palliative care to be met by expanding the workforce of specialists in palliative care. It is more likely that a solution will be found by expanding the knowledge and skills of health professionals generally. There is good evidence that the knowledge and attitudes of primary care professionals about palliative care can be improved, but there will need to be two-way education between specialists and generalists. If people with illnesses other than cancer are to have better access to specialist care, specialists themselves will need to learn more about symptoms other than those caused by cancer.

Policy implications

1. Policy- and decision-makers should ensure that palliative care is a core part of the training and continuing professional education of doctors, nurses, social workers, chaplains and other health professionals.
2. Sufficient palliative care specialists should be trained and supported to provide this education.
3. Health care organizations need to invest in supporting health professionals in keeping up to date with palliative care, especially in pain and symptom management, in developing and maintaining their assessment and communication skills, and in using all available resources.
4. Health care organizations need to develop cultures and working practices that allow the best use of the palliative care skills of health professionals, including spending sufficient time with patients and families.

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The dissatisfied dead cannot noise abroad the negligence they have experienced

Hinton, 1967

Public discussion of death

It is increasingly said that with advances in public health, living conditions and life expectancy, people in developed countries have lost the familiarity that previous generations had with death and dying. The loss of strong religious and spiritual beliefs may also have taken away a language and framework within which people can talk easily about death. Indeed, death may be so far from daily experience that its possibility may be denied or come as a surprise. Medicine is also charged with promoting the view that death is a failure, rather than something normal that may be put off but that will happen eventually. On the other hand, much of the daily news and popular art and music present us with images of the death of other people – often sudden, untimely and the fault of someone else. Sometimes, however, the media presents people who lived well with serious illness until death, and inspired or contributed to the community.

Personal experience

Most adults have experienced the death of at least one relative or friend. The public support given to the hospice movement both in terms of finance and the time and skills of volunteers is testimony to the importance people place on this care. For example, a recent initiative in Croatia recruited volunteers who eventually became involved in weekly home care visits to patients. Now there are 10 000 visits each year. Indeed, people who are dying are among the most vulnerable, and the quality of care they receive must be one mark of society's humanity as a whole.

Innovative public health programmes have a role in educating the public about end-of-life issues and pal-

liative care. This can begin in schools. For example, the National Council for Hospice and Specialist Palliative Care (UK) has produced guidance for teachers looking after children who have recently been bereaved.

Programmes can present more positive images of what good care can achieve. They can increase awareness of different care options for people needing to secure care for older relatives, and lead to more public scrutiny and pressure to implement policies to meet their needs. An increase in awareness about what is known and what is uncertain about causes of death, and what can be offered, may allow people to consider more realistically the choices they will want to make for themselves in the future.

Policy implications

The success and growth of the hospice and palliative care movement is testimony to the importance the public gives to high-quality care towards the end of life. Already, there are effective examples of public education programmes that have explored this issue, using popular culture, the media, music, art and literature. Often, bringing the stories of people and their families or caregivers out into the open is a powerful way of stimulating debate and action.

1. Public health policies must include a component of public education to increase awareness of palliative care issues.
2. This should go beyond traditional adult education courses to reach people from a wide range of communities, using a variety of media.

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Research and training in palliative care should be considered a priority, and funded in line with that for potentially curative interventions

Gaps in research on effective care

This booklet has shown how evidence for needs towards the end of life and for the effectiveness of palliative care has accumulated over the last 40 years. It also shows where there are still gaps in our knowledge. Research is urgently needed into the etiology and treatment of non-cancer pain and symptoms, barriers to accessing care, and the care of patients with diseases other than cancer. Areas needing more in-depth study include the care of older people and those from different cultural groups, the social, psychological and spiritual aspects of palliative care, and the development of assessment tools. A continuing challenge for researchers is how to study and determine needs in a sensitive way, and to synthesize patients' and relatives' views with other evidence to find effective solutions.

Better use also needs to be made of existing data on palliative care, and in developing measures to routinely monitor emerging needs and the quality of care. Useful areas for comparison include variation in models and costs of care and spending on palliative care services, and intercountry research. An important question is how indicators may be meaningfully used to compare care. These might include morphine use, the proportion of non-cancer patients cared for, the proportion of patients who die in pain, and palliative support for patients in nursing homes.

Gaps in research on getting evidence into practice

Once research has established evidence of needs and of effective interventions, considerable work remains to be done in translating this work into everyday prac-

- **The United Kingdom spends only 0.18% of its total government and charitable funding for cancer research on end-of-life and palliative care.**

- **The United States spends only 0.9% of its cancer research budget on palliative care.**

tice within the health services. There is a need for developmental funding of initiatives to educate professionals at different stages of their careers, to improve their skills in assessing needs and changing practice. Methods to coordinate palliative care between professionals working in different settings need to be tested in demonstration projects.

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Implications for policy-makers and research funders

Despite the importance of palliative care for everybody, it does not attract a very high proportion of research funding. Several countries have recently reviewed their national research strategies for cancer research, and have found that less than 0.5% of funding is used on research into palliative care. Set against the fact that more than half of those diagnosed with cancer will eventually die from their disease, this is a staggeringly small figure.

1. Policy-makers need to develop national strategies for palliative care research, and to expand investment in this area across all diseases.
2. Policy-makers should invest in developing national data sets for palliative care.
3. Those funding research should monitor the proportion of funds in any disease area directed towards palliative care, and invest in research to redress imbalances.
4. Those funding research need to encourage innovative research (ideas that are most likely to make a difference in practice) to help people with serious chronic illnesses to live well and die well.

We are grateful to the following experts who were invited to comment on this booklet, many of whom gave us useful comments, graphs, information and reports

Australia
Professor Ian Maddocks
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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.