



What are the palliative care needs of older people and how might they be met?

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ABSTRACT

This is a Health Evidence Network (HEN) synthesis report on the palliative care needs of older people and how they might be met. Ageing populations are characteristic of many countries. More people will need help at the end of life, in a social context of changing family structure and wider migration, employment and ageing of potential care-givers. Despite evidence of dramatically increased need for supportive and palliative care, this area has been relatively neglected in health policy and research.

Coordinated care allows more people to die at home, if they wish, and specialist palliative care is associated with a range of better outcomes for patients and their families. There is also some evidence for the role of palliative care for cardiovascular, respiratory and dementia patients. Although further research is important, the more pressing issue is to implement existing knowledge and sustain improvements in palliative care practice throughout health care systems.

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Summary

The issue

Ageing populations are characteristic of many countries. The pattern of disease at the end of life is changing and more people are living with serious chronic circulatory and respiratory diseases as well as with cancer. More people will need help at the end of life, in a social context of changing family structure and wider migration, employment and ageing of potential care-givers. Despite evidence of dramatically increased need for supportive and palliative care, this area has been relatively neglected in health policy and research.

Findings

There is evidence on unmet needs among older people in the areas of pain relief, information, communication and preferences for place of care. Systematic reviews show evidence of effective pain relief methods and means of training health professionals to communicate well and give information to people with cancer. Coordinated care allows more people to die at home, if they wish, and specialist palliative care is associated with a range of better outcomes for patients and their families. There is also some evidence for the role of palliative care for cardiovascular, respiratory and dementia patients.

Evidence for the effectiveness of simple measures in these areas and for the role of coordinated team care, home nursing, and specialist palliative care is based mostly on studies of people with cancer. There are gaps in the evidence base for palliative care for older people with other serious chronic illness. But in many cases the needs and solutions are likely to be similar to those for people living with cancer.

Policy considerations

Although further research is important, the more pressing issue is to implement existing knowledge and sustain improvements in palliative care practice throughout health care systems. More specifically, policies are needed to encourage:

- investment in research on effective palliative care and treatment for older people with all serious chronic illnesses as well as cancer;
- funding and support for those treatments, actions, and coordinated multidisciplinary services shown to be effective;
- development of high standards for palliative care in pain and symptom management, communication skills and coordination of care; and
- investing in quality improvement methods, and rewarding health care organizations for their involvement, and expanding education and training for staff providing palliative care.

The author of this HEN synthesis report is:

Dr Elizabeth Davies
PhD, MFPH, Senior Clinical Research Fellow
Department of Palliative Care and Policy,
Guy's, King's and St Thomas' School of Medicine
Weston Education Centre
Cutcombe Road
London SE5 9RJ, United Kingdom
Tel: +442078485516
Fax: +440207848 5517
Email: Elizabeth.Davies@kcl.ac.uk

Introduction

Many countries have experienced dramatic improvements in population life expectancy. The proportion of elderly people, and particularly those over 80, has increased significantly in recent decades (1,2). As populations age, people die in greater numbers after long illnesses from heart disease, cerebrovascular disease including stroke, chronic respiratory disease and respiratory infections, and cancer. Predictions suggest that these will be the five main global causes of death in twenty years (3).

It is still controversial whether increased longevity is inevitably accompanied by longer periods of disability towards the end of life. Some recent predictions suggest an optimistic picture, with disability declining in successive cohorts of people as they age (4). Women also consistently live longer than men; some figures suggest as long as six years, and this means nearly twice as many women as men living to the age of 80 (2). In addition 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 (5). As more people survive into old age and begin to suffer chronic illnesses more will need some form of help towards the end of life whilst the age of potential caregivers is increasing as well.

Palliative care offers a support system to help patients live as actively as possible until death. It affirms life and regards dying as a normal process, but intends neither to hasten or prolong it. Using a team approach, palliative care addresses the needs of patients and their families, including bereavement counselling if necessary. It should be offered as needs develop, before they become unmanageable, and must not be something that only specialized palliative care teams, palliative care services or hospices offer when other treatment has been withdrawn. Palliative care can take place in any setting (6,7), and has been defined as:

the total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Palliative care is concerned both with patients and their families and with the enhancement of quality of life from an early stage in a life-threatening illness (6).

Sources for this review

Systematic reviews were identified from searching the Cochrane library, database of systematic reviews (DARE), and Medline for 1998-2003. A major source of reviews was the Palliative and Supportive Care strategy for Cancer being developed by the National Institute for Clinical Excellence in the United Kingdom, which had already searched EMBASE, CINAHL, CancerLit up until 2001. Other information on large studies, gaps in the literature, issues for implementation and policy implications were informed by a World Health Organization working group of experts in palliative care and by an extensive consultation within Europe and the US. The conclusions - *Palliative Care* –

The Solid Facts (<http://www.euro.who.int/document/E82931.pdf>) and *Better Palliative Care for Older People* (<http://www.euro.who.int/document/E82933.pdf>) are published by the WHO Regional Office for Europe in 2004. Each report contains additional comparative information, illustrations, resources and recommendations for policy makers.

The strength of the types of evidence used in this synthesis follows the grading of evidence used in systematic reviews accepted to the standards and quality assurance procedures required for the DARE and Cochrane databases and for the National Institute for Clinical Excellence in the United Kingdom.

Findings

The unmet palliative care needs of older people and their families

Pain

Community surveys consistently find that pain is an important symptom for around one-third of older people. This problem makes people feel less positive about their health and is bad enough to limit activities in around one-fifth of people, although it tends to be under-reported and under treated (8).

Pain also affects 55% to 95% of patients with advanced cancer, and multi-centre studies in France and the United States show inadequate pain relief in about one-half of patients. Unrelieved cancer pain has a serious affect on the quality of life, interfering with sleep, daily activity, enjoyment of life and social interaction (9).

Issues for non-cancer illnesses

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 periods of gradual return to near previous function (10). There has been considerable progress in treating symptoms and crises, but patients often have difficulty understanding and managing the complex drug regimens required and have less formal knowledge of their diagnosis and prognosis. Families also report poor coordination of care and difficulty forming a relationship with any single professional because of multiple-admissions during crises (11,12,13).

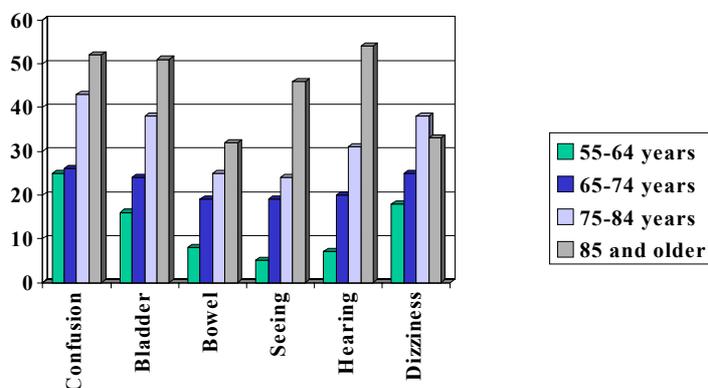
Dementia affects 4% of people over age 70, increasing to 13% over age 80 (14). The median length of survival from diagnosis to death is eight years and during this time there is a progressive deterioration in ability and awareness. Common symptoms include mental confusion, urinary incontinence, pain, low mood, constipation and loss of appetite (15). The physical and emotional burden on family members is well-documented, as is their grief at slowly losing the loved one (16).

Multiple problems of ageing

Older people are more commonly affected by multiple comorbid problems. Minor problems may have a greater psychological impact and the cumulative effect of these may be much greater than that of any single disease. Older people are at greater risk of adverse drug reactions and of iatrogenic illness and suffer the additional problems of mental impairment, economic hardship, and social isolation. This is shown most clearly by epidemiological studies asking key informants about the symptoms experienced by people in the last year of life (17). In particular, seeing, hearing, bladder and bowel control difficulties, mental confusion and dizziness all increase with age. The problems causing suffering include, therefore, those that are regarded as "the troubles of old age," as well as those due to death-causing diseases (17).

Age at death and prevalence of problems reported for the year before death

Source: Seale and Cartwright 1994 ¹⁷



Concerns about communication and patient-centred care

The last few decades have seen consistent findings that cancer services do not always meet patients' needs for communication, information and support. Systematic reviews find strong evidence that patients value accurate information, that many feel they receive insufficient explanation and that doctors and nurses currently have limited ability to detect patients' needs (18). Although there are methodological problems with "satisfaction" measures and international comparisons because of differences in social and cultural expectations, survey data do suggest that patients identify similar kinds of problems in different countries. 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 (19). Many studies of people diagnosed with life-threatening illnesses reveal that the way in which they are told information and 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 (20).

Preferences for place of care and place of death

In most countries over 90% of people over 65 live at home (21). Between 50% and 70% of people receiving care for a serious illness say they would prefer home care at the end of life (22). As death approaches some may wish to accept care in an inpatient hospice, hospital, elderly care home, or nursing or residential facility. In most countries a majority of people actually die in hospital. However, variations in the proportion of people dying at home suggest this is related to the organization and delivery of services rather than peoples' preferences. In most countries an increasing proportion of deaths occur in nursing homes.

Palliative care interventions - evidence from systematic reviews

Most of the systematic reviews identified a concern for patients receiving palliative care for cancer. As three-quarters of people who die from cancer are over 65 years old, the conclusions of these reviews are highly relevant to older people. Although derived from studies of cancer patients, many of these findings are likely to be relevant to older people living with other serious chronic illnesses. The holistic approach of palliative care covers a wide range of topics and these are considered in turn.

Pain and symptom control

Observational studies show that when clinical guidelines on pain control are followed 70% to 97% of patients with advanced cancer gain adequate pain relief. Although research on implementation has

been relatively neglected, educational interventions can improve the knowledge and attitudes of staff about pain though not necessarily patients' pain levels. There is most evidence for brief interventions where nurses encourage patients to complete pain diaries and doctors use explicit mechanisms to ensure pain is assessed daily and that drug dosage is adjusted accordingly (9).

Communication skills

Effective communication between doctors and patients is associated with a range of health outcomes including improved psychological health, symptoms and function, and better control of pain, blood pressure and blood glucose (23). The communication skills of health professionals – including senior doctors, doctors-in-training and nurses – can be improved by education, using feedback from videotaped consultations and discussion, but professionals need help to sustain new skills in everyday practice (24).

Recordings or summaries of key consultations have most benefit for patients with cancer, allowing a better knowledge and recall of information and improved satisfaction (25) without causing psychological problems (26). However, for patients with a poor prognosis, account must be taken of their preference to know the full facts or not (27). In general, decision-making aids can help professionals explain treatments, clarify patient concerns and improve their satisfaction (28).

Psychological support

A wide range of psychological interventions have been tested in over 150 randomized trials over 40 years. Results have been mixed and tend to vary by disease site and follow-up period, with no sustained positive outcomes. Most evidence is for adjuvant psychological therapy but more work is required to identify specific needs and how to target patients for intervention (29,30).

Spiritual support

Spiritual needs are highly personal and important 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 individual coping and outcome among patients and response to bereavement among relatives (31), but it is uncertain whether prayers by others on their own affect outcome (32).

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 settings, studies have so far been too hampered by lack of standard definition, small size, poor response rates, and inadequate measurement to draw any adequate conclusions (33).

Services for caregivers and families

A range of services including home care, respite and “sitting” services, activities within social networks, support groups and individual psychotherapy or education have been developed. Caregivers 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 care-givers and realistic expectations for such services (34).

Coordination and integration of care

One important issue for the care of older people is the transfer of information between those with responsibility for their medical care and those providing social support services in the community. Current mechanisms are often inadequate and although there is little empirical research in the area, a “key worker” seems the most effective way of transferring information (35,36).

Trials of different methods of coordinating services between the hospital and the community 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 the care-givers can be improved if coordinated support is provided (37).

Specialist palliative care teams

A common model for delivering palliative care has been to concentrate expertise in multi-professional teams working in inpatient units, hospitals or the community. These teams usually deal with a selected group of patients with the most complex needs, who have been referred by other teams of professionals. Despite conflicting findings in initial reviews (38-44), meta-analysis now shows small but significant benefits as measured by pain control and other symptoms and expressed care satisfaction by patients and their families (45-48).

Palliative day care

There is evidence that patients value attendance at palliative day care units where they can meet other patients, talk to staff and become involved in activities. There is no evidence as yet that attendance affects other outcomes such as quality of life or symptom control (49).

Bereavement support

Several studies find that the relatives of patients dying in the care of specialist palliative care services report fewer psychological symptoms and unmet needs than the relatives of patients receiving standard care (50). Assessing the need for bereavement support and counselling is regarded as an important part of palliative care, but there is relatively little evidence for the predictive power of assessments targeting individuals or the benefits of individual therapy (50,51).

Involving users in the design of services

There has been recent interest in involving patients in the design and planning of services to ensure they provide more patient-centred care. Preliminary reviews suggest that in general this affects the provision of some aspects of care and may change the culture of health care organizations. However, patients and staff may require training to learn how to carry out this new role most effectively (52,53,54).

Palliative care interventions - evidence from non-systematic reviews

No systematic reviews of palliative care for older people living with illnesses other than cancer could be found for this synthesis. Based on non-systematic reviews of research evidence we found the following.

Specialist nurses for patients with chronic disease

Specialist nurses do not appear to improve communication or pain relief for patients with heart failure, but they do seem to reduce multiple admissions, suggesting a role for a home-based approach to continuing care in selected cases (10). Patients under the care of respiratory nurses live longer, with no improved quality of life, but nonetheless value the visits (55).

Hospice care for patients with dementia

Many ethical issues are also raised by the care of people with dementia who are unable to communicate their wishes. 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. There is limited evidence that hospice programmes for patients with dementia are feasible and associated with less discomfort for patients than traditional long-term care (15).

Gaps and conflicts in the evidence

Research on meeting the palliative care needs of people suffering and dying from the main diseases other than cancer is less well advanced, with few systematic reviews. It is highly likely that many of the more general issues – such as the need for good symptom control, communication, and coordinated care – will be similar for all older people living with other serious chronic illnesses. However, the comparatively uncertain prognoses for these illnesses make it more difficult to plan services around the illness trajectory in the way that has traditionally been done for cancer. A better

approach for older people with other serious illnesses is palliative care based on need, and consideration of the likelihood of death within a few years, as opposed to months, as has been the model of care developed for cancer patients (56).

There is little specific evidence about the effectiveness of intensive care (57), nursing home or residential home care in meeting the palliative care needs older people (58), nor on the needs of people aged over 80 in any setting. In general, there is a lack of evidence from implementation research on how to get established evidence into practice.

Generalizability

The systematic reviews carried out to date have so far only included studies published in English. Much of the work has been carried out in the United Kingdom but work from France, Italy, and Scandinavia shows consistent findings for the role of pain control, coordinated care, and specialist palliative care in cancer. It is highly likely that evidence on the need for effective care in these areas will apply to all countries, although cultural values will affect the kind of communication and the extent of information people desire. Coordination of care and good nursing services across hospital and community settings will be equally relevant, although the details of implementation will depend on the organization of primary care services in each country.

Current debate

Issues in current debates in this field include the best service models to meet the needs of illness trajectories other than cancer where the prognosis is more difficult to predict and whether specialist palliative care services include the skill, knowledge and manpower to meet the wider needs of patients with non-cancer illnesses.

Discussion

Dutch health policy on palliative care (59) is probably the most advanced in having recognized the need to develop services fully across a range of settings. Most people in the Netherlands die at home. Dutch policy developed in part as a result of open public debate about suffering at the end of life that might lead people to ask for euthanasia and how such suffering might be prevented.

In the United Kingdom, the hospice movement has successfully grown and inspired programmes in many other countries. Palliative care began as a movement on the fringe of medicine and its principles have gradually been absorbed into mainstream practice. Cancer is the first disease area to be covered by specific guidance from the National Institute for Clinical Excellence for supportive and palliative care.

There are no reviews of the cost-effectiveness of palliative care and general doubts about whether such methods are appropriate to measure the value of small improvements over the short periods of time that palliative care is likely to achieve.

Failure to develop palliative care policies may lead to unnecessary suffering, increased burdens on families and older women involved in unpaid caring work.

Some of the ongoing projects in the field:

- *Palliative Care – the Solid Facts*. WHO Regional Office for Europe, 2004. (<http://www.euro.who.int/document/E82931.pdf>) (60)
- *Better Palliative Care for older People*. WHO Regional Office for Europe, 2004. (<http://www.euro.who.int/document/E82933.pdf>) (61)

- *Linking Levels of Care*. World Health Organization Regional Office for Europe. <http://www.euro.who.int/integratedcare>. Accessed 20 March 2004.
- *The European Association of Palliative Care Coordination Centre for Eastern Europe*. www.eapcnet.org/projects/east.asp. Accessed 20 March 2004.
- Review of the effectiveness of primary care education in improving palliative care. Dr T Beynon, Department of Palliative Care, St Thomas' Hospital, London
Contact: Teresa.Beynon@kcl.ac.uk
- The European Observatory on Health Care Systems is collecting information on palliative care services in Europe.
- In the United States, an extensive "State of the Science" review for the National Institutes of Health on research priorities for the palliative care needs of older people and possible models of care will be presented by Dr Joanne Lynn and colleagues in December, 2004. Contact: jlynn@rand.org.
- "Setting out a Road Map for implementing the WHO reports on palliative care" Autumn, 2004 Conference, Lake Bellagio, funded by the Rockefeller Foundation.
- Project on Hospice and Palliative Care in Europe (collecting comparative data on service development). Marcel.R.Globisch@sowi.uni-giessen.de.

Present trends

Most European countries, including those in Eastern Europe, are developing or interested in developing palliative care policies.

Conclusions

1. Although population ageing means that most people who die are over 65 years of age and the proportion of people living past 80 years of age is increasing, palliative care for older people dying from diseases other than cancer has been relatively neglected in health research and policy.
2. There is evidence of unmet need for pain relief, good communication, and meeting preferences for place of care for older people. Evidence for the effectiveness of simple measures in these areas, and for the role of coordinated team care, home nursing and specialist palliative care, is based mostly from studies of people with cancer.
3. There are gaps in the evidence for palliative care for older people with serious chronic illnesses. In many cases, however, the needs and solutions are likely to be similar to those identified for people living with cancer. Although further research is important, the more pressing issue is to implement existing knowledge and to sustain changes in palliative care practice throughout health care systems.

Policy considerations

1. Raising awareness of the implications that ageing populations have for the palliative care of over 65, particularly those over 80. This would include investing in research into effective palliative care and treatment for those living with all serious chronic illnesses as well as cancer, and into the current care variations among and within countries (60,61).
2. Ensuring that information about the range of palliative care services available and their effectiveness is fully disseminated within in each country. This would also mean ensuring that those coordinated multidisciplinary services shown to be effective are adequately funded and supported within health services (60,61).

3. Providing practical help for the implementation of effective new care or the more systematic application of existing knowledge within health services. This would mean demanding high standards for palliative care in pain and symptom management, communication skills and coordination of care, investing in quality improvement methods and rewarding health care organizations for their involvement (60,61).

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