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Dying with cancer, living well with advanced cancer

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ABSTRACT

Introduction. There are 1.7 million deaths from cancer in Europe each year and by 2020 the World Health Organisation (WHO) estimates that, globally, more than 15 million people will experience cancer and 10 million will die from it each year. Furthermore, as new therapies are developed, people are living longer with cancer than in the past, and the population with cancer will be older.

Materials and methods. We used epidemiologically based needs assessment approaches to estimate the number of people in Europe with symptoms and problems, published data and reviews to appraise treatment options, issues of communication, family care, bereavement and socio-demographic factors affecting care, and a European survey to consider the types of services. In addition, we used systematic literature review data to appraise the effectiveness of services and factors affecting place of death.

Results. The quality of life of virtually all cancer patients with advanced disease is impaired by one or more symptoms, emotional, social, spiritual and communication concerns. Patients have a median of 11 symptoms. In Europe there are up to 1.6 million patients with pain each year, and in around one third of these it will be severe, requiring complex treatment. Almost an equal number are affected by fatigue, and more than 1 in 2 are affected by anxiety and/or depression, breathlessness, insomnia, nausea, constipation and/or anorexia. There is a complex interaction of factors affecting place of death – related to illness, the individual and environment – and although most people want to die at home, in most countries the majority of cancer patients die in hospital. In response to patient and family needs, systematic review shows the effectiveness of palliative care services. However, the distribution of services across Europe is inequitable.

Conclusion. Palliative care is becoming increasingly recognised as a vital component of cancer care, but requires investment in research, education and services, incorporating appropriate needs assessment and outcome measurements.

1. Introduction

Why is it important to devote attention to people with advanced cancer and those who die from it in Europe? There are four epidemiological reasons. First, it affects very many people – at present, there are more than 1.7 million deaths from cancer in Europe each year.[1] By 2020, the World Health Organisation (WHO) estimates that, globally, more than 15 million people will experience cancer and 10 million will die from it each year,[2] a 60% increase in deaths. In Western Europe, the number of people who die from cancer will increase by 31% to over 630,000 each year (Table 1).

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Table 1 – Deaths from cancer in Europe and selected other parts of the world: 2000 and predicted for 2020

	Number of deaths 2000	Predicted deaths 2020	% Increase
Northern Europe	245 000	310 000	27
Southern Europe	342 400	419 600	23
Eastern Europe	638 200	765 500	20
Western Europe	483 700	631 300	31
TOTAL Europe	1 709 300	2 126 400	24
North America	636 000	962 100	51
South America	458 700	840 900	83
Sub-Saharan Africa	316 300	523 600	66
GLOBAL	6 200 000	10 000 000	61

Source: WHO, 2003.[2]

Second, despite extensive efforts to prevent and cure cancer, overall 5-year survival from cancer is only between 50% and 60% in high-income countries. Optimal treatment combined with early detection leads to a high rate of cure or remission for some cancers (e.g. of the cervix, breast, oral cavity and colon; and lymphomas).[3] Yet, survival remains poor for some cancers (e.g. of the oesophagus, pancreas and lung). Third, these improvements in the early detection and management of cancer have meant that cancer patients live with their illness for longer than in the past. The transition from radical, intensive treatment to a phase of less active life-prolonging treatment and palliative care remains poorly understood. Fourth, the general ageing of the population will mean that people who have cancer are older. Other chronic and progressive diseases will also become more common, among all people affected by cancer, both patients and their families or caregivers. This brings with it problems of co-morbidity for those people with cancer, so that their health needs become much more complex, as well as leading to changes in the structure of society, with more and more older people living alone or at a distance from their family.

However, there is also a fifth reason – not epidemiological, but perhaps the most important. Patients with advanced cancer can experience profound symptoms, which, unless alleviated, result in great suffering for them and their family.[4,5] There are emotional, social and spiritual consequences associated with cancer, disability and facing the end of life, for patients, their families and those close to them.[4,6] All these require effective support, communication and care. The effects on the family can continue long into bereavement, affecting their subsequent health and well-being.

In response to these needs, and the demands of patients and families for effective and coordinated support at this phase of the illness, most European countries have developed palliative care services. As Dame Cicely Saunders, the founder of the modern palliative care movement, explained: '*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*'.[4]

2. Materials and methods

Advanced cancer brings with it a complex web of problems, all of which interact with each other. We review first the functional changes and the emergence of symptoms, and the emotional, social and spiritual effects on the individual, including coping with the impact of loss and the challenge of facing impending death.[4] Using the methods of Higginson [7] to develop an epidemiological assessment of need for palliative and terminal care, we estimated the likely annual numbers of people in Europe with advanced cancer. We then applied symptom prevalence data to the numbers of cancer deaths in Europe to suggest the numbers with symptoms in the last year of life. We reviewed the management of these symptoms, the other dimensions of care that need treatment, the socio-economic impacts, communication, the needs of the family and caregivers, variations in and place of cancer death, and bereavement. Using data from a survey by the European Association for Palliative Care Task Force on the Development of Palliative Care in Europe (http://www.eapcnet.org/download/forTaskforces/developTF-Map.pdf) we appraise the types of services in Europe and finally, appraising key systematic reviews, we appraise the evidence of effectiveness of palliative care services.

3. Results

3.1. *Functional trajectories*

Much attention has been given to the functional decline that accompanies cancer. This is probably because chemotherapy trials often study functional status as a proxy for quality of life. In the United States, Lynn and colleagues modelled the trajectory of functional decline in cancer and other conditions.[8] As Fig. 1 suggests, they propose a period of stable (good) function, followed by a period of rapid decline. However, the data on which this model was validated is based on cross-sectional data collected on different patients at different times before death.

Therefore we cannot be sure that these trajectories reflect the longitudinal trajectory of individual patients. Further, as the cancer population has aged, with concomitant co-morbidity, and treatments have evolved, giving second, third and even fourth line chemotherapies and improved surgery and radiotherapy for palliative effect, it is likely that the trajectory of cancer patients is less smooth than that in the Figure, and may even be more like that of organ failure or frailty.

3.2. *Cancer symptoms – how many people in Europe are affected?*

Symptoms are very common in advanced cancer, with patients having a median of 11 symptoms on admission to palliative care services.[9] Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common; occurring in some combination in virtually all patients.[5] Our epidemiological assessment of need for palliative and terminal care suggests that there are, among patients who eventually die of their cancer, up to 1.6 million patients with pain each year

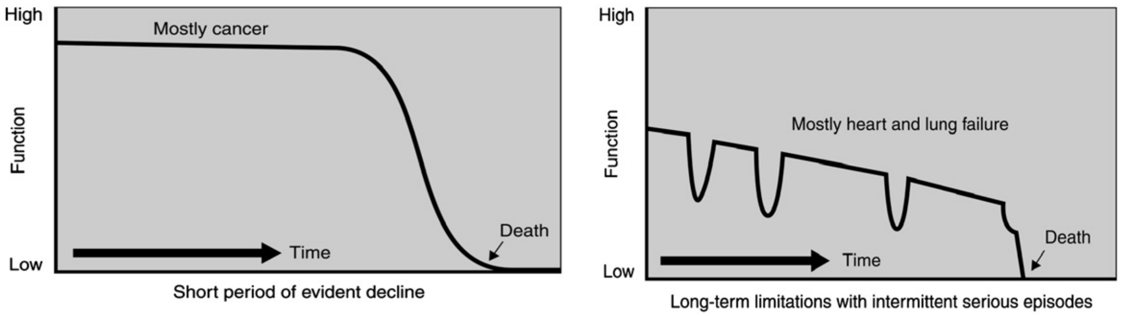

Fig. 1 – Hypothesised trajectories of functional decline in cancer and other conditions (which may now represent the cancer trajectory). *Source:*Lynn & Adamson, 2003.[8]

(Table 2). In around one third of patients this pain will be severe, requiring complex treatment.[7,9]

There have been many advances in the management of symptoms. It is beyond the scope of this chapter to review these, and major textbooks, e.g. *Palliative Medicine* - Dying with cancer, living well with advanced cancer,[10] and *The Oxford Textbook of Palliative Medicine*,[11] deal with these developments. Needless to say, pain and many other symptoms can often be treated effectively. Treatment requires impeccable assessment of cause (there may be overlapping symptoms caused by the cancer, treatment or co-morbid conditions) and effects, and skill in using analgesics to balance effect on pain against

Table 2 – Cancer patients: prevalence of symptoms and estimated number of cancer patients with symptoms towards the end of life

Symptom	Symptom prevalence (%) in advanced cancer according to systematic review (A) (no. of patients)	Symptom prevalence (%) in a random sample of people in the last year of life (B)	Number of cancer patients in Europe experiencing the symptom each year (C) (lowest possible - highest)
Pain	35–96 (10 379)	84	595 000 – 1 632 000
Depression	3–77 (4 378)	38	51 000 – 1 309 000
Anxiety	13–79 (3 274)	N/A	221 000 – 1 343 000
Confusion	6–93 (9 154)	33	102 000 – 1 581 000
Fatigue	32–90 (2 888)	N/A	544 000 – 1 530 000
Breathlessness	10–70 (10 029)	47	170 000 – 1 190 000
Insomnia	9–69 (5 606)	51	153 000 – 1 173 000
Nausea	6–68 (9 140)	51	102 000 – 1 171 810
Constipation	23–65 (7 602)	47	391 000 – 1 105 000
Diarrhoea	3–29 (3 392)	N/A	51 000 – 493 000
Anorexia	30–92 (9 113)	71	510 000 – 1 564 000
Loss of bladder control	N/A	37	629 000
Loss of bowel control	N/A	25	425 000
Unpleasant smell	N/A	19	323 000
Bedsores	N/A	28	476 000

Notes: (A) Symptoms as per Solano, Gomes and Higginson (2006), based on a systematic review of symptoms in advanced cancer[5]. Range is the range of prevalence found in the study, no. patients is the number of patients included in the studies.
(B) Symptoms as per Cartwright and Seale studies [52,53], based on a random sample of deaths and using the reports of bereaved carers about the last year of life.
(C) Estimated number of patients with symptoms in Europe based on prevalence and 1.7 million cancer deaths. Range is lowest to highest, prevalence is higher when patients are near the end of life. The true figure is likely to lie between the ranges, probably nearer the top end, as the prevalence in the last year of life suggests. Note: patients are most likely to have multiple symptoms.
*Source:*Method of calculation based on Higginson, 1997 [7].

potential side effects, including constipation (which should always be anticipated and pre-empted), nausea and confusion. There is a need to balance these with the individual's psychological, social and spiritual problems, as it is important to treat the total person and not fragments of them. For example, sleep quality is related to pain, feelings of hopelessness and pain treatment in advanced cancer patients.[12]

In 1986, WHO published simple but effective guidance on the management of pain. This 'analgesic ladder' proposed non-opioid analgesics as the first step, followed by a mild opioid (step 2) or strong opioids (step 3) in patients with persistent pain. Non-opioid drugs (including non-steroidal anti-inflammatory drugs – NSAIDs) are effective analgesics for patients with mild cancer pain and can be combined with opioids in patients with moderate to severe pain. Importantly, drugs should be given orally (wherever possible) and regularly, rather than waiting for pain to break through.[13]

Pain management has advanced considerably in recent decades, although the WHO approach remains at the heart of practice. There are new analgesics, different routes of administration (e.g. sublingual, subcutaneous, transdermal, intra-nasal), long and short acting medications for different pain durations, techniques to manage neuropathic pain (which involves the nerves and is most difficult to treat) and research into methods to 'switch' opioids, which may be useful if side effects are problematic, in instances of renal failure and, in some cases, to improve effectiveness of pain relief.[13]

Study of other symptoms and interactions between symptoms lags behind that on pain, but nevertheless shows promising progress for many symptoms, including constipation, nausea, vomiting and breathlessness, although fatigue and anorexia remain problematic for many.

3.3. *Emotional concerns*

Psychological and emotional concerns are common in advanced cancer but may be dismissed by professionals and, sometimes, by the patient's family. In-depth discussion is often needed to identify the causes of the problems and these may be quite different from what one might expect. There are many interwoven factors that may include the family, finances, spiritual needs, guilt, anger, fear of dying and unrelieved physical symptoms. The patient may employ different defence mechanisms and coping strategies, some of which may be unexpected or difficult to interpret. Understanding these mechanisms can help carers to explain and empathise with a patient's behaviour. It is only when the mechanisms are excessive that problems occur – for example, excessive introjection can result in self-blame, isolation and depression; excessive projection can result in alienation of friends and family members or paranoid states; excessive displacement can lead to complete exhaustion followed by severe depression or anxiety.

The stress of prolonged illness or the shock of a recent diagnosis of advanced cancer can predispose a person to psychiatric and psychological problems, particularly if they have few external supports (for example, if they live alone, have few friends, or are very poor), have limited communication skills (such as in learning difficulties or impaired vision or hearing), or if they have a history of mental health problems. Assessment and management requires skill and a multiprofessional multimodal approach.[14,15] Assessing psychological problems can be complex, but there are now simple screening methods that work well in advanced cancer.[16,17]

3.4. *Socioeconomic impacts*

First in the United States and then in Europe,[18] surveys have revealed the socioeconomic impact of terminal disease on both patient and caregiver. Of 1271 caregivers interviewed in the Italian Survey of Dying of Cancer – ISDOC,[18,19] 44% reported difficulties in their regular employment during the last 3 months of the patient's life. Of the 68% of families who had to pay for some of the care: 37% had to pay for drugs; 36% for nursing and assistance; and 22% for physicians. In order to cover the costs of patient care, 26% of families in this Italian survey and 31% in a similar American survey[20] used all or most of their savings. In the Italian survey, the duration of time the patient was completely dependent strongly determined the effect that caregiving had on the caregiver's regular employment and on the family's financial situation.

There are also differences between ethnic groups. A mortality followback survey in the United Kingdom found that a comparable proportion of caregivers of 50 black Caribbean and 50 white British patients reported experiencing restrictions in activities of daily living during their last year of life which included needing help toileting, washing and shaving; and requiring help at night. However, significantly more (70%, $n = 26$) black Caribbean respondents stated they needed more help assisting their dependants with these tasks compared to 33% ($n = 14$) of those caring for white dependants. Significantly more respondents caring for black Caribbean dependants also reported that they gave up visiting friends and relatives, going out for social occasions, and entertaining people at home, although similar numbers from both ethnic groups reported that they found the overall experience of providing care was rewarding.[21]

3.5. *Relationships and communication*

In all European countries, communication about cancer can be very problematic. Training programmes have been developed and evaluated for many of the critical points in cancer care, including breaking bad news, truth-telling, explaining treatment options and giving information about clinical trials. However, end-of-life care is least studied. Studies of patients with far advanced and progressive illness, or of their bereaved carers, identify three main areas of communication that are important:

1. information giving, with an empathetic approach from professionals to patients;
2. communication between the patient and their family regarding end of life issues;
3. communication between the different professionals involved in care, such as between doctors and nurses and between community and inpatient settings, to avoid contradictory or redundant information and ambiguity.[14]

In a study across three European countries, data were collected on 1326 patients: 416 in the United Kingdom, 411 in Ireland and 499 in Italy. Severe communication problems at the end of life were found among up to 40% of patients.[14] Problematic communication was more common where the patient had respiratory or breast cancers and a shorter time in palliative care.

Talking to patients about the end of life is especially difficult. In a study of bereaved family members whose relatives had died from cancer (50 from the black Caribbean Community and 50 from the white British community), in both groups over two thirds of patients knew they might die, although in over half of these cases no one had actually told them this.[22] In an Italian study only 12% of patients dying from cancer had received information about the bad prognosis of the disease, although according to the caregivers half of the patients had realised their poor prognosis.[23]

3.6. *The family and lay caregivers*

Concern for the patient and family, as the unit of care, is an essential element in the care of people who are dying. The word ‘family’ is meant in its broadest sense and encompasses close relatives (often a spouse, children or siblings), a partner and close friend(s) who are significant for the patient. End of life places a particular strain on families and on relationships.[24] Families should have every available option to meet their choices, and expert recognition of their cultural and individual needs. Not everyone will have the time to embark on long family discussions, but everyone can recognise the family or carers by name and accept them as an integral part of the team caring for the patient. This includes acknowledging the concerns of the family or friends and finding mechanisms for these to be heard and discussed, whether care is at home, in hospital or in a hospice.

The evidence supporting this approach is two-fold. Firstly, descriptive studies provide evidence of dissatisfaction and problems when involvement of the family does not occur.[25] Secondly, there is evidence from comparative and descriptive studies in Europe and the United States of higher satisfaction among carers when services do provide these family support systems. A systematic review of both comparative and randomised studies affirmed this, although many of the studies were small, retrospective and used matched (rather than randomly allocated) groups.[15]

3.7. *Place of death*

For many people, home is more than a physical space – it represents familiarity, the presence of loved ones and the possibility of enjoying ‘normal’ life. These are the reasons why systematic reviews of studies of preferences have found that more than 50% of people with a progressive illness want to die at home [26]. Several countries are making substantial efforts to enhance home care, prompted by increased commitments to users’ choice, rapidly increasing elderly populations, the quest to maximise scarce resources, and the experience of nearly four decades of palliative care practice.

Despite these efforts, preliminary data reported in the WHO analysis of palliative care[4] and more recent publications[27,28] showed that most patients in England and Wales, the United States, Germany, Switzerland, France, Italy and Belgium, die in hospitals (Fig. 2).

A conceptual model derived from the results of a systematic review, including 58 studies referring to over 1.5 million patients from 13 countries, shows the complex interaction of factors – related to illness, the individual and environment – which influence place of death (Fig. 3).[29]

Even though people often wish to die in their own homes, the probability of doing so is often lowest in areas of high socioeconomic deprivation (Fig. 4).[30–32] This is an important finding because those in poor areas tend to require more resources to achieve the same level of care. A study in London compared the activity of home palliative care nurses in deprived and affluent areas. It found that to achieve similar levels of home death rates, at least twice as many visits were needed in the deprived areas.[33]

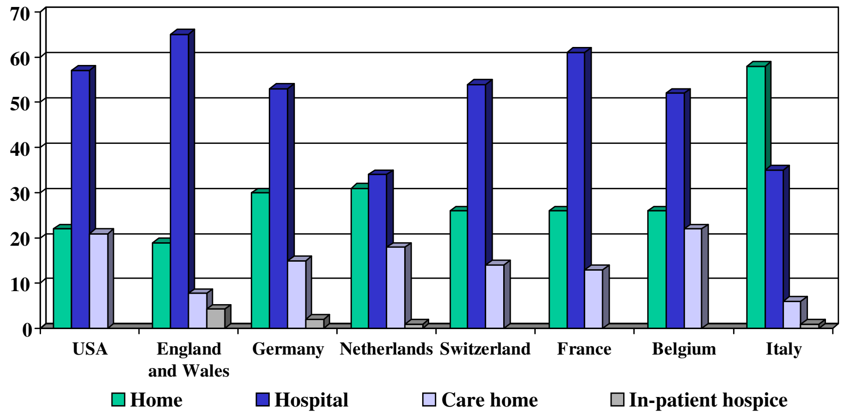

Fig. 2 – Preliminary data on place of death by country. *Sources:*Davies & Higginson, 2004[4]. Updated with data from Cohen J, et al., 2007 [28] for Belgium and with data from Beccaro M, et al., 2006 for Italy [27]. *Note:*Data from different countries are collected in different ways and sometimes not 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. The 15% of deaths that occur in residential homes for the elderly in the Netherlands are not included in the graph.

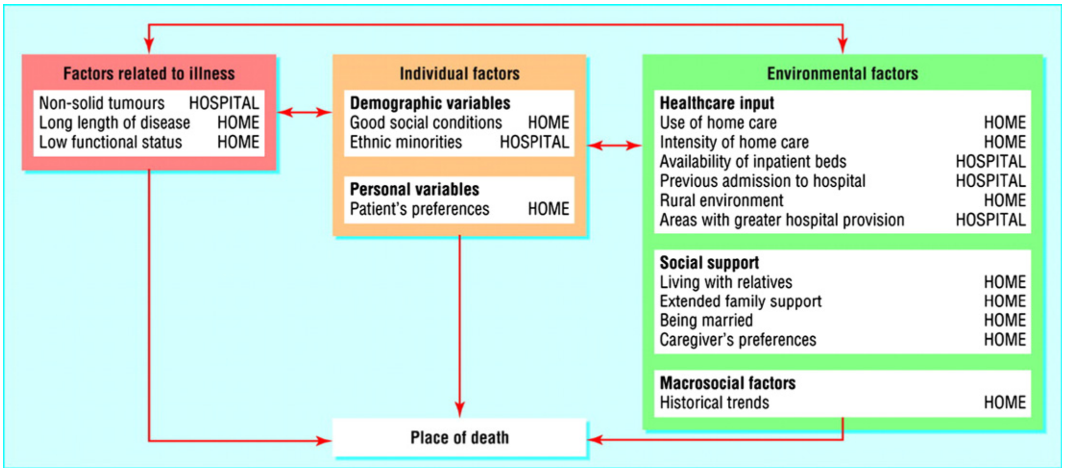

Fig. 3 – Model derived from a systematic review (including 1.5 million patients) of the factors associated with home or hospital death. ***Source:*****Gomes & Higginson, 2006.**[29]

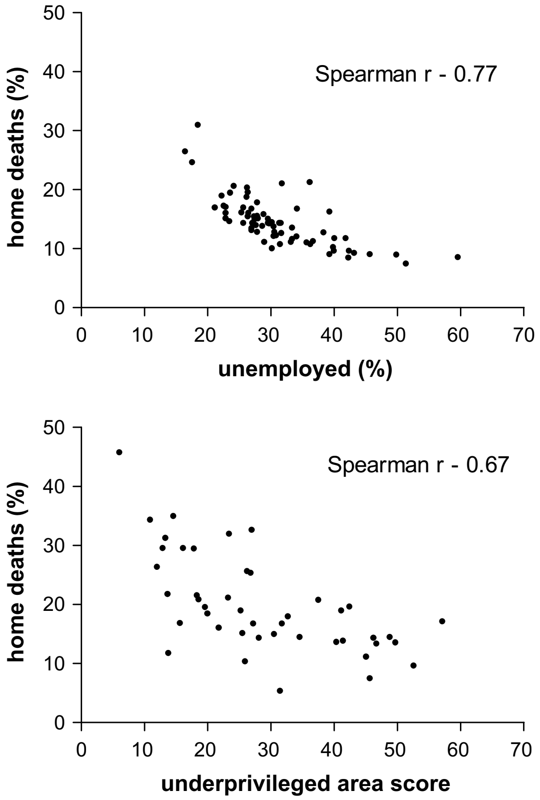

Fig. 4 – Results of two ecological studies in Genoa (top) and London (bottom) to analyse the relationship between the proportion of people who died at home and social indicators. Source: Costantini, Fusco & Bruzzi, 1996;[30] Higginson, Webb & Lessof, 1994.[31]

The inverse care law often operates in relation to hospice care, with provision inversely related to need. This is because hospice services are often supported by voluntary contributions, which are easier to raise in more affluent areas. In a comparison of home cancer deaths in London and New York, Decker and Higginson also found that in both cities, in all age groups, home deaths were less common in the lowest socio-economic groups.[34]

3.8. *Bereavement*

Bereavement refers to a loss through death of someone significant. A universal occurrence, bereavement is also an especially potent and stressful life event. It predisposes people to physical and mental illness, can precipitate illness and death and aggravate existing illness.[35] Although there is considerable variability in the rate at which individuals adjust to bereavement, most literature indicates that in western societies most bereaved people return to normal activities one to two years after their loss. Grief related distress is normally highest in the first year. According to classical definitions, a chronic, persistent, intensive, inhibited or delayed grief is regarded as pathological or complicated. However, any distinction between normal and pathological grief must take account of cultural differences. Grief is universally experienced, but response to loss is culturally bound. Unrestrained crying, wailing, self mutilation or prostration may be a normal expression of grief in some societies.[35]

Recognising the needs of the family and caregivers both before and after bereavement is important in cancer care. Before the death occurs, family members may begin to express 'anticipatory grief' of the death and may grieve the loss of previous relationships with the person before their death. Individual and situational factors can affect the outcome of the grieving process. These include: protracted illness, difficult or uncontrolled symptoms, a stigmatised death, the nature of the relationship, life circumstances, a history of physical and/or mental health problems, and isolation.

Principles of support in advanced cancer and after death should include viewing the patient and family as the unit of care; enabling open discussion of illness and death-related concerns; providing emotional support; facilitating practical systems; and respecting cultural, ethnic and spiritual practices.

Much attention has been given to adult grief, but bereaved children raise particular issues. A review of factors affecting children's reactions to bereavement found that truancy and behaviour problems were more common among bereaved children and adolescents. Social factors were important mediators of the response. More affluent and better supported children appeared to be buffered against major difficulties, whereas those from socially deprived circumstances or lacking supportive family environments experienced more severe and complicated grief.[36] These social circumstances were more important in influencing outcomes than were service factors, such as support offered to children. Schools may play an important role in supporting children among their peers, but rarely are teachers equipped or trained to facilitate open discussions of children's concerns.

For the minority of individuals who experience pathological grief, there is a need for rapid referral to appropriate services. However, many questions regarding bereavement remain unanswered. How common is complicated grief? Which interventions support what proportion of bereaved people most cost-effectively? And when is the right time to identify individuals and commence an intervention?

3.9. *Palliative care services*

Palliative care services have developed in culturally appropriate ways across Europe. While this has meant that services have responded to regional variations in health- and social-care structures, it has also led to variations in definitions, models and processes of care within, as well as between, countries.

Hospices and specialist palliative care services have increased rapidly in number worldwide. In 2007 there were over 8000 hospice or palliative care services in 100 countries of the world. In 2006, there were well over 1500 hospice and palliative care services in Europe. The number of services per million population ranged from 0 to over 20. However, these data are difficult to interpret because of variations in the definition and size of responding services, the use of self-assessments, and missing data and differences in the interpretation of the questions.

The main types of services within Europe include those listed below.

- **Inpatient hospice and specialist palliative care units with dedicated beds.** The term hospice and palliative care are often used interchangeably across Europe. The term palliative care is more appropriate in some countries, because the term hospice means hospital in some Latin-based languages and so confuses the public and policy-makers. Some inpatient units are freestanding, being managed independently from and geographically separated from hospitals. Many of these are charitable units, a very few are private and some are part of community services. There are also inpatient units within acute hospitals, and in some instances part of a hospital ward is dedicated to palliative care.
- **Hospital-based palliative care teams.** Usually these are advisory peripatetic teams that provide support, advice and education in the management of dying patients within the hospital. They are sometimes called mobile teams. These services rarely 'take over' the management of patients and more usually advise the clinicians in charge of care on symptom management, as well as supporting the family and facilitating communication, care planning and discharge to the community or an in-patient hospice. They are often involved in multidisciplinary team meetings and may do joint ward rounds with oncologists or other specialists.
- **Home care teams** provide support for patients and their families in the community. They usually work in partnership with existing community services, especially the family doctor or general practitioner and district nurses. They are most often advisory and do not provide 'hands-on' nursing care, such as washing, dressing etc. However, this varies from country to country. For example, in Italy the community palliative care team takes over all aspects of community care, including direct care and prescribing; in the United Kingdom the services negotiate their level of support and usually prescribing and direct physical care is provided by the primary care team and social services. These teams may be based in the community, in hospital or in freestanding hospices or palliative care units.
- **Day care services** are offered by inpatient units and home care teams. This model of care has developed primarily in the United Kingdom and is found much less often in other European countries. Patients usually attend day care centres one day per week, for the whole day, and are offered individualised services ranging from therapies (including complementary therapies), to mutual support, social and personal care activities such as bathing and hairdressing, and artistic and musical activities.
- **Outpatient services** are sometimes offered by all the above services, offering clinic attendance for patients in the community.
- **Bereavement services** are offered by many inpatient palliative care and hospice services, and by some home care, day care and hospital teams. Often, volunteers are involved in visiting families and sometimes group support is offered.

One feature common to all the above models is that of the multidisciplinary team. This is a key component of the approach to palliative care. The specialists that may be included in a multiprofessional palliative care team include doctors, clinical nurse specialists, social workers, chaplains, therapists and psychologists or psychiatrists. The team should aim to:

- achieve accurate and speedy assessment and diagnosis of the problems;
- plan and implement effective integrated treatment and care;
- communicate effectively with the patient, family and all other professionals and agencies involved in the care of the patient, and within the team;
- audit activities and outcomes.

A systematic review of the effectiveness of palliative care teams identified 44 relevant studies.[15] Of these, 26 included data suitable for meta-analysis, including randomised controlled trials and comparative or observational studies.

Table 3 – Summary of results from a meta-analysis of a multiprofessional palliative care team compared with conventional care - description of the effect size for the different patient outcomes

	Pain	Other symptoms	QOL	Satisfaction	Referral	Therapeutic interventions	All studies	Excluding outlier[a]
Studies (*n*)	20	14	17	5	1	4	26	25
Mean effect	0.41	0.32	0.18	0.38	0.24	0.52	0.33	0.26
SD	0.50	0.48	0.41	0.27	–	0.40	0.50	0.36
Min	−0.14	−0.11	−0.62	0.05	–	0.03	−0.62	−0.62
Max	2.04	1.76	0.87	0.69	–	0.98	2.04	0.98
Weighted mean	0.37	0.20	0.20	0.24	–	0.43	0.33	0.32
SE (w mean)	0.13	0.15	0.12	0.14	–	0.23	0.12	0.09
95% CI	(0.11, 0.63)	(−0.10, 0.50)	(−0.04, 0.44)	(−0.04, 0.52)	–	(−0.01, 0.87)	(0.10,0.56)	(0.15, 0.49)

*Source:*Higginson et al., 2003 [15].

a One study had very positive outcomes and so was excluded from this analysis.

Evidence was strongest for the effectiveness of home care studies, but there was also evidence of the effectiveness of hospital teams and inpatient hospices. Comparison of specialist multidisciplinary care and conventional care revealed a small quantitative benefit from multiprofessional teams. The main outcomes to benefit were pain, symptom control and changing the nature of therapies provided (from intensive treatments to human approaches to care) (Table 3).

No studies conducted full cost-effectiveness analyses, but those studies that examined costs showed a tendency for a reduction in hospital inpatient days resulting in lower hospital costs, although this was at the expense of greater costs in the community.

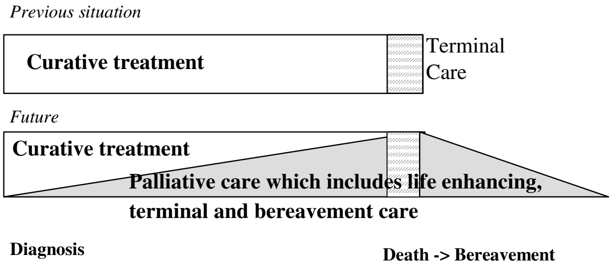

Fig. 5 – Model of palliative care as an increasing part of care from diagnosis onwards.

4. Discussion

4.1. *Extending palliative care to earlier in the illness*

Cancer in Europe is changing, with longer periods of illness and treatments continuing later in the course of the disease. It is becoming more and more like other chronic illnesses. One important question is when palliative care should start? Patients often have symptoms and psychological and social concerns earlier in their illness. Communication is important too. WHO has recommended that palliative care should be begin early in the course of illness. There is a need to move from the idea of palliative care as a rectangle which begins at a specific point close to death, to the concept of an interaction between palliative, life extending and curative treatment, each forming triangles that change in response to patient and family needs over time. Bereavement follow-up is part of this model. The use of shared clinics and ward rounds involving oncologists and palliative care specialists might be one step towards this (Fig. 5).

4.2. *Resilience in advanced cancer disease*

On the other hand, we should not forget that many individuals, families and communities demonstrate great resilience and grow during this period, providing their symptoms and difficulties are adequately managed and they have time to do so. Indeed some patients rate their quality of life very highly during advanced cancer, even higher than before they were ill.[37] Improving our ability to deal with the problems of patients and providing effective services to allow for such growth is a key goal for cancer care.

Research into factors that promote resilience suggest that paying attention to spiritual and psychological well-being, and creating meaningful narratives of living and dying are important.[38] Similarly, Chochinov has developed programmes to improve dignity, which include involving patients in preparing a narrative account of their lives.[39] A key issue is to ensure that patients and families are given the means – if they wish – to live well until they die, as well as to die well.

4.3. *Assessment and outcome measurement*

Assessment of the patient is a critical aspect of palliative care, just as at other times of care. However, the standard measurements (of pulse, blood pressure, temperature and functional status) may be inappropriate at this stage if they do not contribute to planning of care. Appropriate assessment should emphasise pain and symptom control, the quality of life for the patient, fears and anxiety, psychological, social and spiritual concerns, any future wishes and the needs of family members and carers. This approach is equally relevant in clinical care and in measuring outcomes in research studies.[40–42]

There is now a range of validated assessment tools that have been developed and validated in the palliative care setting. The Palliative Care Outcome Scale – POS (and its precursor measure, the Support Team Assessment Schedule) has been validated in community, hospital and inpatient hospice settings, and featured user involvement during its design.[41–43] The POS has been independently validated and translated into several European and African languages.[44–48] There are also adaptations to well-known measures such as the FACT and EORTC QLQ-C30 for palliative care.[49,50]

However, several challenges remain. Measures must be short and simple enough for use in patients with severe illness. They can be completed by proxy informants where patients have cognitive impairment, although more research is needed on the validity of this approach.[51] There is a crucial need to standardise the measures used, in both research and clinical practice. Currently, a group involving King's College London (in partnership with European networks) is attempting to establish a Europe-wide project to test the use of POS and related measures, understand what measures are used and which are needed, and provide web-based resources. In addition, a systematic review is being undertaken by a collaborative group in the United Kingdom, supported by the National.

Cancer Research Institute. This is using Delphi exercises and statistical analysis to develop common measures and methods to map from one measure to another.

4.4. *Ageing of the population with cancer*

People with cancer are growing older, and increasingly, may experience not just one cancer, but may be cured from an initial one and then experience another cancer in later life. Furthermore, older people have multiple co-morbidities that can influence their treatment options, increase the risk of side effects from drugs and exacerbate symptoms and problems. The cancer specialist of the future will be dealing more and more with older people. This will require a strong understanding of general medical issues, unless patients are to be seen by multiple specialists, which may be time consuming for them and impractical if they are more frail.

This is also an issue for palliative care. Palliative care services and treatments will have to find ways to support and manage patients not only in hospitals and specialist units, but also nursing and residential homes, and to deal with patients who live alone, far from their families. They will need a better understanding of the management of diseases, symptoms and emotional concerns in diseases other than cancer.

4.5. *Recommendations for the future*

Looking ahead, it is possible to identify four areas that require attention.

4.5.1. *Needs assessment*

Hospices and palliative care services have developed in a haphazard way, often in response to local initiatives and support by champions. Although this type of development often reflects local wishes and circumstances, it means that hospices and palliative care services may not be in the places where they are most needed and may be disconnected from effective services. Epidemiologically based needs assessment should drive future developments, coupled with statutory support, to reduce the inverse care law that applies to the provision of palliative care services.

Although many types of palliative care services have been evaluated, there is a need to compare the costs and benefits of variations in the mix of care (home versus hospital versus hospice) along with full evaluations of some of the new models of care, such as palliative care beds within hospitals, day care services and earlier integration with other professionals. Based on these results European guidance of models of best practice are needed, especially focussed on some of the growing populations, such as for older people.

4.5.2. *Investment in research*

In the United Kingdom, less than 0.2% of research spending in cancer addresses palliative and end-of-life care. The figure is not known for many other European countries, but is likely to be similar. Research in palliative care therapies and services needs to be prioritised, along with methodological development to further refine the study designs, measures and methods.

4.5.3. *Education and training in palliative care*

A curriculum for palliative care doctors exists in the United Kingdom, and to some extent in other European countries. A curriculum for nurses in palliative care does not exist. There is a need for curricula relevant to different types of clinicians, such as oncologists, as well as for specialists in palliative care.

4.5.4. *Assessment*

This is a strategic and clinical necessity. European statistics about place of care, symptom levels and family concerns are not available. Such information is needed to understand and contrast provision and outcomes across Europe to aid policy-makers and public health physicians in the development of palliative care in the future. At the clinical level, assessment and outcome tools exist and have been translated and validated in several countries. European collaborative efforts are required to develop these tools further and to make them more widely available.

4.6. *Conclusions*

Palliative care is an essential component of cancer care. Its importance is becoming increasingly recognised but it requires investment in research, education and services, incorporating appropriate needs assessment and outcome measurements, if it is to achieve its potential to improve the quality of care for cancer patients and their families and help them live well until they die, as well as to die well. Engaging appropriately in palliative care is important for society. It is often during advanced cancer that the family engage with health care. Receiving good care at this time will make it easier for family members to, in the future, adopt preventive measures, engage in treatment and present early. Conversely, poor care will lead to fear and delays in presentation.

Conflict of interest statement

None declared.

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