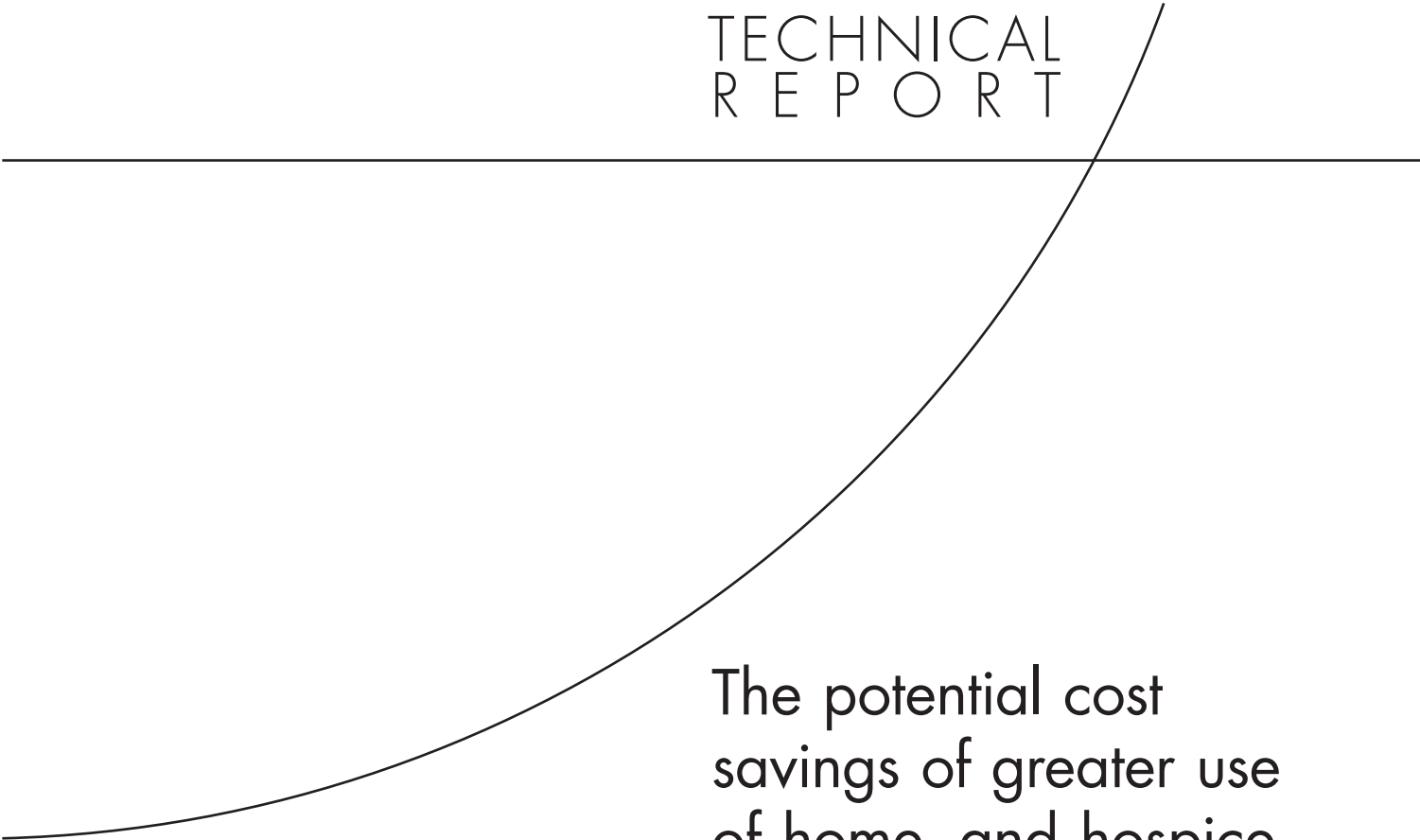


The potential cost savings of greater use of home- and hospice-based end of life care in England

Evi Hatziaandreu, Fragiskos Archontakis,
Andrew Daly in conjunction with the
National Audit Office



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Prepared for the National Audit Office

The research described in this report was prepared for the National Audit Office.

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Preface

This report has been commissioned by, and prepared for and in collaboration with, the National Audit Office (NAO). Its objective is to provide an estimation of the current financial impact of caring for patients during their last year (365 days) of life in England and to simulate the expected benefits of expanding the reach of palliative care services and respecting peoples' expressed wishes for the place where they want to receive care at the end of their life.

This study contributes to the limited economic literature on the economics of palliative care. It demonstrates the benefits of increasing the reach of palliative care services and improving the quality of care while avoiding hospitalisations that do not offer additional benefits to patients close to the end of their life.

This report will be of interest to healthcare providers, healthcare users, healthcare insurers and policy makers.

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For more information about RAND Europe or this document, please contact:

Dr. Evi Hatziaandreu
RAND Europe
Westbrook Centre, Milton Road
Cambridge CB4 1YG
United Kingdom
Tel: +44 1223 353329
Email: evih@rand.org
www.rand.org/randeurope

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Summary

The National Audit Office (NAO) commissioned and worked with RAND Europe to estimate the current economic impact of end of life care in England and examine the potential implications of expansion of those services. This commissioned study is part of a broader Value for Money study that the NAO is undertaking into end of life care in England (see Box 1). This is a timely and important issue to consider not only because of the challenges ongoing demographic trends will impose on the system, but also because, as evidence suggests, there is unmet need for palliative care and end of life care services. As importantly, while the majority of people express the wish to die at home, most people (two out of three) die in hospital. The implications are clear: a recent study showed that if past trends in terms of reductions in home deaths continue, in order to meet the projected increase in the numbers of annual deaths (585,000 in 2030) there would be a need to expand inpatient facilities by over 20%.

Box 1: End of life care as defined by the National Council for Palliative Care

End of life care “Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.”¹

There is an increasing distinction between **end of life care** and **palliative care**. The latter is being accepted to cover patients of any age of advanced and life-threatening illness who may still be receiving curative care and are not considered to be in their last 6–12 months of their life.

The objective of this study is to explore and provide estimates of the financial consequences of decreasing reliance on acute care during the last year of life. The present study has two distinct phases. The first reviews the end of life and palliative care literature for evidence of effectiveness and resource utilisation. The second phase is the economic analysis of end of life care in England which: a) provides an overview of the current costs to the NHS for delivering services to patients (under current usage levels of palliative care services) in England, and b) models and quantifies the potential cost implications of

¹ National Council for Palliative Care. 2007. *Building on Firm Foundations: Improving End of Life Care in Care Homes: Examples of Innovative Practice*, London: NCPC, June 2007. <http://www.ncpc.org.uk/download/publications/BuildingOnFirmFoundations.pdf> (accessed 6 October 2008).

decreasing reliance on acute care during the last year of life by higher levels of adoption of palliative care services.

The review of the literature revealed that there is consistent and robust evidence that palliative care services reduce the symptom burden and improves satisfaction and quality of life of patients and caregivers. Almost all studies that look at costs find economic benefits for palliative care; the evidence is clearer for cancer patients and predominantly from the United States. Any savings result from fewer hospitalisations and reduced use of intensive acute care resources.

To progress the economic analysis for England, we developed an economic model (a Markov model), which uses health expenditures and utilisation data. We then used the model to: a) estimate the current cost (to the NHS) of healthcare provision of end of life care for patients who are in their last year of their life and suffer from cancer or organ failure (pulmonary and heart failure), and b) simulate various scenarios of reduced acute care utilisation by those patients and measure the economic implications. The implicit assumption is that the time patients spend in hospitals could be reduced by transferring them to their preferred care setting at the end of their life. By providing end of life care in the community both the number of unplanned emergency admissions and the days spent in hospital could be decreased. With the use of the economic model we estimate the days of acute care which could be potentially avoided as well as the associated amount of resources which could be made available for redeployment.

Overall, results show the estimated cost of providing care in the last year of life to the nearly 127,000 patients who died from cancer is approximately £1.8 billion, corresponding to £14,236 per patient. For the nearly 30,000 organ failure (heart and respiratory diseases combined) patients that are in their last year of life the cost of providing care is £553 million, or £18,771 per patient. Sensitivity analysis indicated that overall costs of caring for cancer patients are substantially influenced by the cost of providing home/community care. A 10% variation in the daily cost can decrease or increase total costs by £122 million in a single year.

The simulation of different scenarios that examine decreases in the proportion of unplanned admissions for cancer patients (5–20%) and in the corresponding length of stay from 1 to 5 days (of those admissions) show expected reductions in expenditures ranging from £42 to £171 million per annum.

Overall, the study results consistently point in the same direction as the literature: there is real potential for palliative care services to reduce expenditures associated with hospitalisation while at the same time accommodating the expressed preferences of patients.

Acknowledgments

This report is a product of a study that has been conducted in close cooperation with the NAO team: Tom McBride, Andy Nichols, Karen Jackson and Alec Morton. We gratefully acknowledge their significant contribution, support and insights. Their deep understanding of the policy considerations was valuable in making this study relevant to policy makers. The analysis of key data that were made available by the NAO was integral to making the results of the study robust and solid. We would also like to thank Professor Irene Higginson for her valuable comments and suggestions.

The National Audit Office (NAO) commissioned RAND Europe to model, study and estimate the current economic consequences of end of life care in England and examine the potential implications that expansion and improvements of those services could have. Indeed, this is a timely consideration of an issue receiving increasing attention and focus from policy makers.

The causes and nature of illness are changing; we are living longer and survival from diseases is prolonged. Current life expectancy in England is expected to increase from 78.3 years to 82.8 years in 2039 (males), and from 82.1 to 86.3 years (females).² The proportion of those aged 65+ is expected to rise from 16% in 2004 to 23% in 2020. Males are expected to live an extra 2.9 years, and females an extra 3.7. In parallel, the number of people aged 80 and over is growing rapidly. In the past 30 years the largest proportion in growth in the population was among those aged 85+ (5.9%). In 2009 the population in this age group will be 2.4 million and by 2029 those aged 80+ will be 4.3 million. Increases in life expectancy will bring increases in progressive incurable, chronic diseases, and larger numbers will be coping with serious impairments later in life. This increase in the number of elderly people will lead to an increase in the number of people living with chronic disease and multiple conditions. All of these result in a transformation of the population's health needs and an increasing disease burden.

Currently in England 15.4 million people suffer from chronic diseases, and this group account for a substantial proportion of health expenditure. Almost £8 out of the £10 of the total healthcare bill is spent on health and social care for chronic disease sufferers.³ Analysis of the 2005/06 Hospital Episodes Statistics (HES) indicate that 5% of patients account for 49% of all inpatient bed days. This burden is expected to increase substantially in the future. There will be 18 million people in England by 2020 who will have at least one long-term condition.⁴

It has been estimated that from 2002 to 2020 there will be a 20% increase in the number of new cancer patients each year. In England and Wales more than one out of three people

² http://www.gad.gov.uk/Demography_Data/Life_Tables/Eoltable06.asp (accessed 6 October 2008)

³ Department of Health. 2008. *End of Life Care Strategy. Promoting High-quality Care for All Adults at the End of Life*. London: UK Department of Health, July 2008.

⁴ Belfield, G. 2008. "The role of commissioning in advancing chronic care". Presentation at the *World Healthcare Congress*, Berlin, March 2008

will develop cancer during their lives, and more than the 25% of the population will die from it. At the same time, however, the 5-year survival from cancer is expected to increase from 40% to 50%.⁵

In England each year 470,000 people die.⁶ Thirty-five percent of these deaths are caused by circulatory disease, 27% by cancer, 14% by respiratory disease, 3% by neurological conditions and 1% by renal failure (Figure 1). The majority of all deaths, 58%, occur in acute hospitals (Table 1).⁷

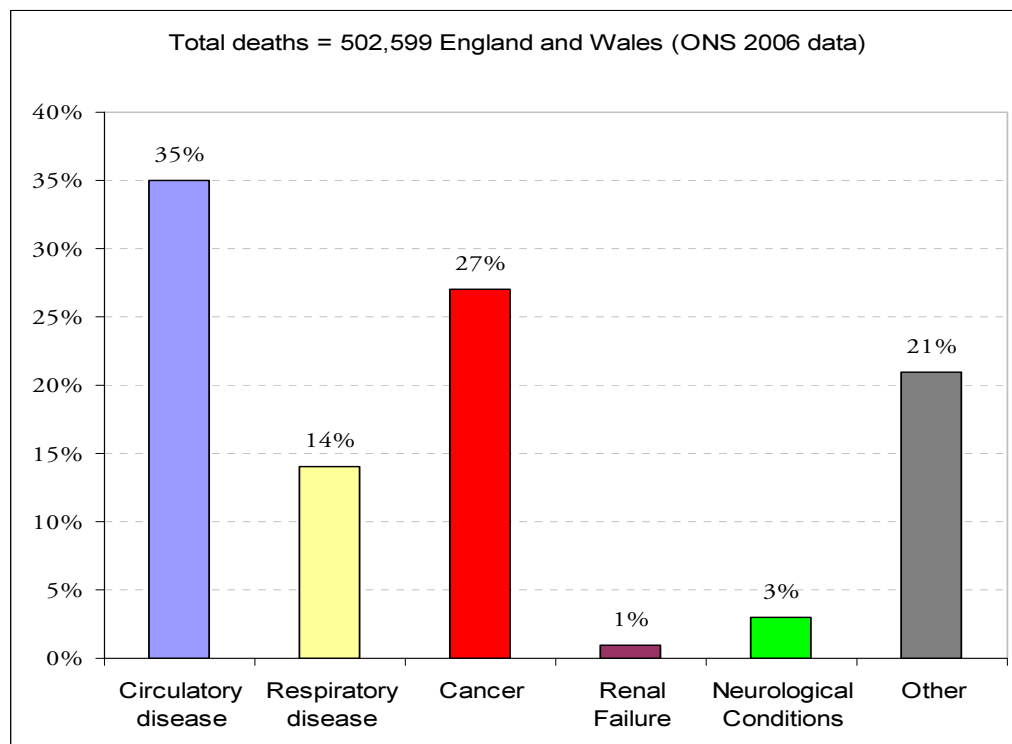


Figure 1: Causes of death by condition in England and Wales, 2006⁸

⁵ National Audit Office. 2004. *Tackling Cancer in England: Saving Lives*. <http://www.nao.org.uk/pn/03-04/0304364.htm> (accessed 6 October 2008)

⁶ Office for National Statistics. 2008. Deaths by local authority of usual residence, numbers and standardised mortality ratios (SMRs) by sex, 2007 registrations. Newport: ONS. http://www.statistics.gov.uk/downloads/theme_population/Table_3_Deaths_Area_Local_Authority.xls (accessed 6 October 2008)

⁷ Department of Health. 2008. *End of Life Care Strategy. Promoting High-quality Care for All Adults at the End of Life*. London: UK Department of Health, July 2008.

⁸ Office for National Statistics. 2008. *Mortality Statistics: 2006*. DR_06. Newport: ONS

Table 1: Place of occurrence of death by underlying cause in England Wales, 2006

Setting/ underlying cause	Pulmonary disease	Heart failure	Dementia	Renal failure	Cancer	Motor neurone disease	Alzheimer's disease	All
Hospital	69.3%	69.4%	38.1%	65.7%	47.5%	46.6%	33.9%	58%
Hospice	0.7%	0.4%	0.1%	1.3%	17.5%	13%	0.1%	5%
Care home	10%	18.1%	54.8%	20.3%	9.7%	13.6%	56.7%	15.4%
Home	19%	10.8%	4.3%	11.5%	23.8%	25.8%	6%	19%
Other	1.1%	1.2%	2.7%	1.2%	1.5%	1%	3.2%	2.6%

SOURCE: Office for National Statistics, 2008

The annual number of deaths is expected to rise by 17% from 2012 to 2030. By that year 585.000 deaths are forecasted. People will be dying increasingly at older ages. Indeed, deaths among the very elderly, those aged 85+, will account for almost 45% of the deaths in 2030.⁹ The shift in degenerative conditions is accompanied by changes in the patterns of death to a more gradual deterioration as the boundaries between being ill and dying have been obscured and prolonged.¹⁰ Thus, end of life is not a related to a brief illness but to a more prolonged period.

These trends have also resource implications. In the United States it is estimated that 20% of healthcare expenditure is related to end of life patients. Patients in their last year of life account for 80% of the Federal Medicare Programme expenditures, half of it by those in their last two months of their life. Similarly, in the United Kingdom about 20% of hospital bed days are covered by end of life care.¹¹ The pattern is expected to be similar in other western European countries. Since medical care provided in hospital consumes more resources and is relatively expensive, reducing undesirable hospital admissions and the intensity of services provided (intensive care unit (ICU), ancillary services, pharmacy, etc.), could reduce the overall financial burden of end of life care^{12,13}.

A growing body of literature suggests that end of life palliative care enabling patients to die at home or in a more home-like setting, such as an inpatient hospice, can provide a better and preferred alternative for 50–70% of people.^{14,15,16} Palliative care concentrates on reducing the severity of disease symptoms for chronic conditions when cure is no longer

⁹ Gomes, B. and I. Higginson. 2008. Where People Die (1974-2030): Past Trends, Future Projections and Implications for Care. *Palliative Medicine* 22: 33–41.

¹⁰ Jakobsson E. 2006. *End of Life Care in a Swedish County*. Goteborg University: Institute of Health and Care Sciences.

¹¹ Higginson I., et al. 2003. Is there Evidence that Palliative Care Teams Alter End of Life Experiences of Patients and their Caregivers? *Journal of Pain Symptom Management* 25:150.

¹² Chochinov, H.M. and K. Janson. 1998. Dying to Pay: the Cost of End of Life Care. *Journal of Palliative Care* 14: 5.

¹³ For a critical perspective, see Luce, J.M. and G.D. Rubenfeld. 2002..Can Health Costs Be Reduced by Limiting Intensive Care at the End of Life? *American Journal of Respiratory and Critical Care Medicine* 165: 750–54.

¹⁴ Finlay, I. 2001. UK Strategies for Palliative Care. *Journal of the Royal Society of Medicine* 94: 437.

¹⁵ Gysels, M., et al. 2003. *Improving Supportive and Palliative Care for Adults with Cancer*, London: National Institute for Clinical Excellence.

¹⁶ Finlay, I. 2002. Palliative Care in Hospital, Hospice, at Home: Results from a Systematic Review. *Annals of Oncology* 13 (Suppl. 4): 257.

feasible. With such care in place, a great number of hospital admissions at the end of life can be prevented while avoiding costly life sustaining interventions.¹⁷ Thus it has been argued that investments in home- or hospice-based palliative care have the potential to improve care without driving up costs.

The recently completed NHS Next Stage Review focused on end of life care as one of its key pathways. The UK Department of Health announced its End of Life Care Strategy in July 2008. The strategy aims to improve access to high-quality care for all people approaching the end of life. It sets out ten specific objectives, from increasing public awareness to ensuring that services provide good value for money for the taxpayer.¹⁸

The objective of the present study was to explore and provide estimates of the financial consequences of decreasing the reliance on acute care during the last year of life. As part of this objective, it aims to shed light on the amount of hospital resource consumption that could be avoided, if palliative care services in the community were increased. This study had two distinct phases. These were as follows: a) the reviewing of the relevant literature in English to obtain evidence about the effectiveness and resource utilisation implications of end of life care, and b) the modelling of the last year of life of patients in England suffering from cancer and organ failure to estimate current resource utilisation and costs. Finally, these results were used as a basis for simulation of different scenarios reflecting different levels of palliative care and examination of their resource use and cost implications.

¹⁷ Thomas, C., et al. 2003. *Place of Death in the Morecambe Bay Area: Patterns of and Preferences for Place of Final Care and Death Among Terminally Ill Cancer Patients and their Carers*. Final report to NHS Research and Development Department. Lancaster University, UK.

¹⁸ Department of Health. 2008. *End of Life Care Strategy. Promoting High-quality Care for All Adults at the End of Life*. London: UK Department of Health, July 2008.

The importance of end of life and palliative care is increasingly being recognised and acknowledged for a variety of reasons. The World Health Organisation (WHO) considers it to be an important public health issue as it is concerned with issues of suffering, dignity, care needs and quality of life of people at the end of their lives.¹⁹ Indeed, leading healthcare organisations call for recognition of “palliative care and pain treatment as basic human rights.”²⁰

Many people die while suffering from severe pain and other distressing symptoms and problems (e.g. breathlessness, nausea, vomiting, loss of appetite, depression, cough, incontinence, etc.). Pain is very prevalent in the last year of life, 90% of cancer patients and 70% of those dying from other terminal illness experienced pain.^{21,22,23} Indeed, a high degree of unmet need remains in the area of pain control.²⁴ While the majority of those patients die in hospitals, many physicians and nurses perceive care for dying patients to be burdensome for the patients themselves, who receive often medically futile care, including unnecessary mechanical ventilation and cardiopulmonary resuscitation.^{25,26} Evidently in many cases, the care offered by hospitals does not match the needs of terminally ill people with a chronic health condition. Whereas hospitals are focused on curing acute

¹⁹ Higginson, I. and E. Davies (Eds.). 2004. *The Solid Facts: Palliative Care*. Brussels: World Health Organization Europe.

²⁰ www.hospicecare.com/resources/pain_pallcare_hr/ (accessed 6 October 2008)

²¹ Higginson, I. and M. Constantini. 2008. “Dying with Cancer, Living Well with Advanced Cancer.” In: M. Coleman, D.M. Alexe, T. Albrecht and M. McKee (eds.). *Responding to the Challenge of Cancer in Europe*. Slovenia: Institute of Public Health of the Republic of Slovenia.

²² Higginson, I., et al. 2003. Is there Evidence that Palliative Care Teams Alter End of Life Experiences of Patients and their Caregivers? *Journal of Pain Symptom Management* 25:150.

²³ Higginson, I. 2008. “To cure sometimes, to relieve often, to comfort always: rediscovering this purpose in palliative care”. Presentation at the University College London, London, April 2008. www.kcl.ac.uk/palliative. (accessed August 2008)

²⁴ Frank, P.J., et al. 2000. The Level of Need for Palliative Care: A Systematic Review of the Literature. *Palliative Medicine*, 14: 93–104.

²⁵ Currie, A. and R. Charlton. 2007. A UK Perspective on Worldwide Inadequacies in Palliative Care Training. *American Journal of Hospice Palliative Care* 20: 1–9.

²⁶ See also Solomon, M. Z., et al. 1993. Decisions Near the End of Life: Professional Views on Life-sustaining Treatments. *American Journal of Public Health* 83: 14–23.

intermittent illness, this group of patients has many other concerns including managing pain and coordinating care among multiple providers.²⁷

Palliative care is specifically aimed at addressing the care needs of (terminally ill) people at the end of their life. It focuses on prevention and relief of suffering by means of early identification and treatment of pain and other problems. In addition to alleviating symptoms, palliative care teams attend to psychosocial concerns by addressing the full spectrum of problems that arise, emotional, social and spiritual for sufferers and carers alike. In addition to those patients at the end of their life, palliative care, could be also offered in parallel with curative, disease-modifying, life-prolonging treatment for those patients that symptom alleviation is warranted.²⁸

The added value of palliative care in terms of quality of life indicators is now well established – although ways of improving the delivery of palliative care are still very much subject to study (for a recent review of the literature, see Lorenz et al., 2008²⁹).

2.1 Principles of end of life care

There is no precise definition of end of life.³⁰ The US National Institutes of Health (2005) has, however, concluded that evidence supports the following as key components of end of life:

- The presence of chronic disease(s), symptoms or functional impairments which may fluctuate but nevertheless persist; and,
- Symptoms or impairments resulting from underlying irreversible disease(s) which require formal or informal care, and which can lead to death.

The National Council for Palliative Care (NCPC) in a working definition of end of life care frames it as the care that:

“Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.”

End of life care stands in contrast with standard medical care. It is care provided where curative (i.e. disease modifying) treatment is no longer available. Moreover, in standard care, there is no special regard to the specific needs of people at the end of their life. End of life care recognises dying as a normal process and its goal is to maximise quality of life. An

²⁷ Lynn, J. and D.M. Adamson. 2003. *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*. Santa Monica: RAND Corporation (WP-137).

²⁸ Brunnhuber, K., S. Nash, D.E. Meier, D.E. Wiessman and J. Woodcock. Spring 2008. *Putting evidence into practice: Palliative care*. British Medical Journal Publishing group.

²⁹ Lorenz, K., et al. 2008. Evidence for Improving Palliative Care at the End of Life: A Systematic Review. *Annals of Internal Medicine* 148: 147.

³⁰ Jakobsson, E. 2006. *End of Life Care in a Swedish County*. Goteborg University: Institute of Health and Care Sciences.

important element is the care and support offered to carers and family after death. Its aims are achieved by ensuring good symptom control, sensitive, culture-specific communication and well coordinated care.³¹ It uses a multidisciplinary team approach to address the needs of patients and carers and to support them.

There is an increasing distinction between the end of life care and palliative care. The latter is being accepted as covering patients of any age who have advanced and life-threatening illness and may still be receiving curative care and who are not considered to be in their last 6–12 months of their life.

Models of end of life care: People approaching the end of life require and may receive palliative care either at a stand-alone hospice, at home through community care services, at a specialist palliative care unit within a hospital, care or nursing home, as well as in other establishments.^{32,33} It is not uncommon that an individual will receive care from two or even three care settings during their end of life/palliative phase.

Economic implications: There is evidence (mostly in the US literature) that palliative care results in cost saving. It lowers costs (for hospitals and payers) by reducing hospital and ICU length of stay and direct (e.g. pharmacy) costs. In addition, it improves continuity between settings and increases hospice and nursing home referral by supporting and enhancing transition management.³⁴ In the UK, Taylor and Carter (2004), analysing data from the Marie Curie Nursing Service, estimate £2 savings for each £1 spent on home palliative and supportive care.³⁵ Miller et al. (2002) cite US\$1.52 savings for each US\$1 spent on hospice services in the US.³⁶ In Spain, a study showed palliative care services policies to improve efficiency (with savings of 61%), with no compromise of patient care.³⁷ A Canadian study showed that introduction of comprehensive community-based palliative care services are cost neutral while they result in increasing service delivery. This financial impact is achieved through the reduced use of acute care beds.³⁸

³¹ Scheffer, R. 2005. "Palliative Care: an essential component of treatment" (Powerpoint Presentation). <http://www.para55.org/reports/22November05/RichardSchefferMalta22Nov05Presentation.pdf>. (accessed 31 October 2008).

³² Department of Health. 2008. *End of Life Care Strategy. Promoting High-quality Care for All Adults at the End of Life*. London: UK Department of Health, p. 21.

³³ Edmonds, P. 2004. Organization of Palliative Care Services. *Medicine*, 32: 2.

³⁴ Meier, D. 2007. "Quality 101: Palliative Care and the Quality Imperative" Presentation at the Center to Advance Palliative care, New York, April 2007.

³⁵ Taylor, D.G. and S. Carter. 2004. Valuing choice – Dying at Home. A Case for Core Equitable Provision of High-Quality Support for People who Wish to Die at Home, UK: Marie Curie Cancer Care.

³⁶ Miller, G., et al. 2002. *Delivering Quality Care and Cost Effectiveness at the End of Life: Building on the 20-Year Success of the Medicare Hospice Benefit*. Virginia, US: National Hospice and Palliative Organization, February 2002.

³⁷ Gomez-Batiste, X., et al. 2006. Resource consumption and costs of palliative care services in Spain: a multicenter prospective study. *J of Pain Symptom Management* 31:522-532.

³⁸ Fassbender, K., et al. 2005. Utilization and Costs of the Introduction of System-wide Palliative Care in Alberta, 1993-2000. *Palliative Medicine* 19: 513.

Target population for end of life care: Until now, palliative care has been focused almost entirely on cancer sufferers. According to the NCPC, 95% of those with access to hospice and specialist palliative care services are cancer patients; there is, however, recent evidence that the proportion of non cancer sufferers receiving other specialist palliative care services has been increasing.^{39,40} In England 17.5% of patients dying from cancer currently die in a hospice; of those who suffer from circulatory and respiratory diseases it is fewer than 1%.^{41,42} Palliative care principles though apply and can benefit patients dying from other chronic degenerative diseases such as organ failure (heart, respiratory, renal), neurological disorders and dementia. There is ample evidence suggesting that such patients have unmet needs, experience similar degree of symptom distress to cancer patients and face their own unique and extensive end of life care challenges.^{43,44,45,46,47,48,49}

³⁹ National Audit Office. 2008. *End of Life Care*. London: NAO, November 2008. www.nao.gov.uk

⁴⁰ National Council for Hospice and Specialist Palliative Care Services. 2004. *The House of Commons Health Committee Inquiry into Palliative Care. Submission of Evidence*. London: NCPC

⁴¹ National Council for Hospice and Specialist Palliative Care Services. 2004. *The House of Commons Health Committee Inquiry into Palliative Care. Submission of Evidence*. London: NCPC

⁴² National Council for Palliative Care. 2004. *The Palliative Care Manifesto*. London: NCPC.

⁴³ Edmonds, P., et al. 2001. A Comparison of the Palliative Care Needs of Patients Dying from Chronic Respiratory Diseases and Lung Cancer. *Palliative Medicine* 15: 287.

⁴⁴ Elkington, H., et al. 2005. The Healthcare Needs of Chronic Obstructive Pulmonary Disease Patients in the Last Year of Life. *Palliative Medicine* 19: 485.

⁴⁵ Beattie, J. 2006. Presentation at "Palliative Care and Heart Failure: Moving Forward Together". London, NCPC Conference. http://www.ncpc.org.uk/download/events/HF_190106/Jim_Beattie_Session_1_19_01_06_HF_Event.pdf (accessed 31 October 2008).

⁴⁶ Connolly, M. 2006. Presentation at "Palliative Care and Heart failure: Moving forward together". London, NCPC Conference. http://www.ncpc.org.uk/download/events/HF_190106/Mike_Connolly_Morning_Session_19_01_06_HF_Event.pdf (accessed 6 October 2008)

⁴⁷ National Council for Hospice and Specialist Palliative Care Services. 2007. *A Fresh Approach: Chronic Respiratory Disease and Palliative Care*. London: NCPC. <http://www.ncpc.org.uk/events/afreshapproach.html>

⁴⁸ Connolly, M. 2006. Presentation at "Palliative Care and Heart failure: Moving forward together". London, NCPC Conference. http://www.ncpc.org.uk/download/events/HF_190106/Mike_Connolly_Morning_Session_19_01_06_HF_Event.pdf (accessed 6 October 2008)

⁴⁹ Davison, S., F. Murtagh and I. Higginson. 2008. Methodological considerations for end-of-life research in patients with chronic kidney disease. *J Nephro* 21: 268-282.

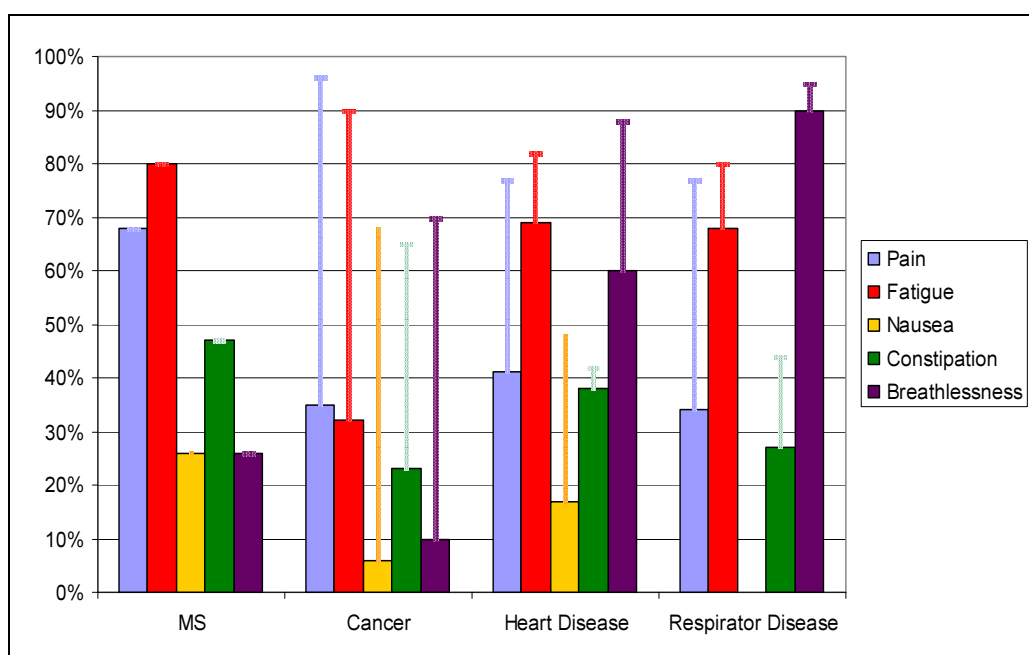


Figure 2: Palliative care symptoms among patients with advanced conditions⁵⁰

Figure 2 shows the prevalence of palliative care symptoms among patients suffering from advanced conditions. It is evident that uncomfortable symptoms affect in similar or higher frequency patients suffering and dying from other terminal conditions.

The need for palliative care: Estimated numbers of people with symptoms, England and Wales^{51,52}

Dying from cancer (140,000 people):

- 66,000 will suffer from breathlessness
- 99,500 will suffer from anorexia
- 105,000 will suffer from weakness/fatigue.

Dying from other progressive conditions (250,000 people):

- 122,000 will suffer from breathlessness
- 94,500 will suffer from anorexia

⁵⁰ Sutton, L. 2008. Presentation "Why the current focus on palliative and end of life care for people with neurological conditions?" NCPCC Conference, London, June 2008. http://www.ncpc.org.uk/download/events/PiecingItTogether_120608/LucySutton%20-%20Part2.pdf (accessed 31 October 2008).

⁵¹ Higginson, I. 1997. "Health Care Needs Assessment: Palliative and Terminal Care." In: Stevens A and Raftery J (Series Eds). *Health Care Needs Assessment*. 2nd Series. Oxford: Radcliffe Medical Press, 1997.

⁵² Solano, J.P., B. Gomes and I.J. Higginson. 2006. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease (COPD), and renal disease. *Journal of Pain and Symptom Management*, 31: 58-69.

- 99,500 will suffer from weakness.

2.2 Place of death and the potential reach of palliative care

Studies of where people suffering with a progressive illness would prefer to die, consistently find that more than 50% (up to 70%) would prefer to do so in their own home.⁵³ It has been stated that 50% of cancer patients is a realistic figure for home care and death if appropriate services are offered.⁵⁴ Preferences may change once a person is in the last months, weeks or days of life. Compared to dying at a hospital, the prospect of dying at home may just “seem safe” to most people – but not at any cost. The underlying preference may be for the feeling safe and secure. This of course can be accomplished in several care settings. For example, in a study of a cohort of 128 patients with incurable cancer, Van der Heide et al. (2007) found no indication that dying in an institution or at home involve major differences in the process and quality of dying.⁵⁵

Nevertheless, the place/setting of death are found to be important determinants of the quality of life at the end of life and to be associated with the carers’ level of satisfaction with the care given during this period.⁵⁶

Ultimately, actual place of death is determined and influenced by a variety of factors.⁵⁷ Utilising results from a systematic review Gomez and Higginson (2006) developed a conceptual model, shown below in Box 2. This model describes the complex interactions of three different types of factors that influence place of death.⁵⁸ These are factors related to the specific illness, to the individual and to the care environment.

⁵³ Department of Health. 2008. *End of Life Care Strategy. Promoting High-quality Care for All Adults at the End of Life*. London: UK Department of Health, July 2008.

⁵⁴ Rosenquist, A., et al. 1999. Optimizing Hospital-Based Home Care for Dying Cancer Patients: A Population-Based Study. *Palliative Medicine* 13: 393.

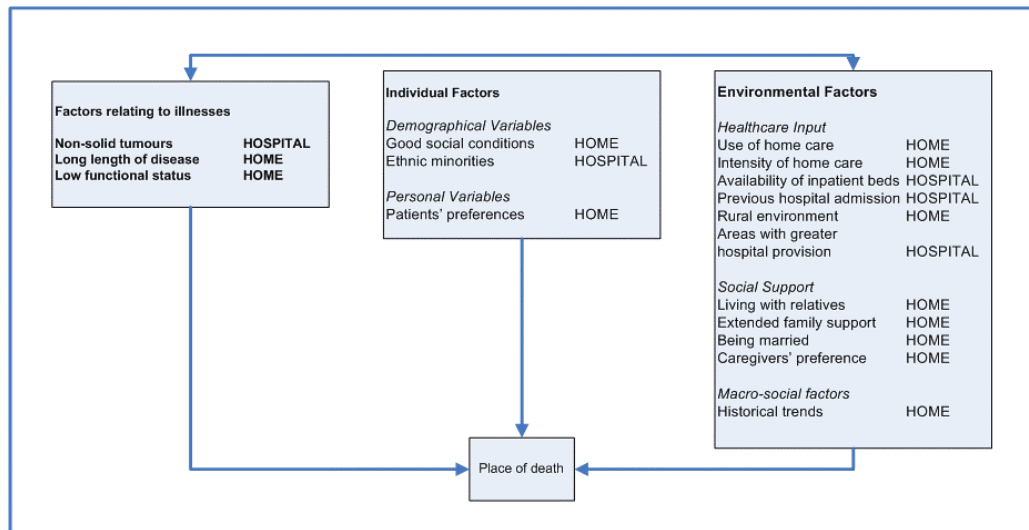
⁵⁵ Van der Heide, A. et al. 2007. Dying at Home or in an Institution: Perspectives of Dutch Physicians and Bereaved Relatives. *Support Care Cancer* 15: 1413.

⁵⁶ Jakobsson, E. 2006. *End of Life Care in a Swedish County*. Goteborg University: Institute of Health and Care Sciences.

⁵⁷ Decker, S.L. and I. Higginson. 2006. A tale of two cities: factors affecting place of cancer death in London and New York. *European Journal of Public Health*: doi:10.1093/eurpub/ckl243

⁵⁸ Gomes, B. and I. Higginson. 2006. Factors Influencing Death at Home in Terminally Ill Patients with Cancer. *British Medical Journal*, 332: 512.

Box 2: Model of factors influencing place of death⁵⁹



England and Wales appear to be lagging behind other countries in terms of the proportion of home deaths, as a high proportion of people die in a hospital. This is particularly pronounced for terminally ill cancer patients: in England, 24% die at home, in the Netherlands 45% and in Italy 58%.⁶⁰ Despite people's stated preferences, data from the WHO shows that most patients in England and Wales (as well as in the US, Germany, Switzerland, France, Italy and Belgium) die in hospitals. Although the reach of palliative care in England is growing, it is still limited. Figure 3 shows (notwithstanding measurement methodological differences) a comparison of seven developed countries; the percentage of people who died in hospital is highest in England and Wales (65% versus 58% in the US, 52% in Germany, and 30% in Ireland).

⁵⁹ Gomes, B. and I. Higginson. 2006. Factors Influencing Death at Home in Terminally Ill Patients with Cancer. *British Medical Journal*, 332: 512.

⁶⁰ Beccaro, M., et al. 2006. Actual and Preferred Place of Death of cancer patients. Results from the Italian Survey of the Dying of Cancer (ISDOC). *Journal of Epidemiology and Community Health* 60: 412.

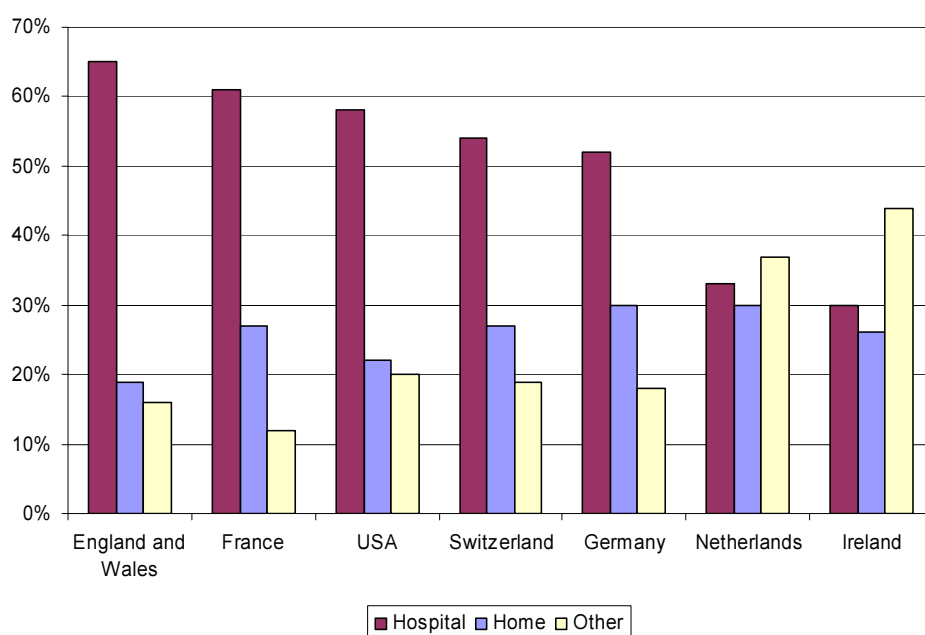


Figure 3: Place of death in 2004⁶¹

2.3 Future end of life care needs

A recent study by Gomes and Higginson (2008) provides some insights into the upcoming challenges that ongoing demographic trends will present to the system and emphasises the urgency of planning to accommodate the expected increases in deaths in England and Wales.⁶² The number of annual deaths is forecast to increase from 512,000 in 2005 to 585,000 in 2030. In this case, numbers of home deaths would need to increase by:⁶³

- 13,500 (14% increase), to maintain the 2005 home death percentage of 18.4%
- 88,000 (94% increase), to restore the 1974 home death level percentage
- Almost 200,000 (212% increase), if percentage of home deaths is to reflect individual preferences.

Alternatively, the study indicates that if past trends “of reducing home deaths continue, there will need to be a large expansion (by over one-fifth) of inpatient facilities.”

⁶¹ World Health Organization Europe. 2004. *Better Palliative Care for Older People*. Brussels: WHO Europe

⁶² Gomes, B. and I. Higginson. 2008. Where People Die (1974-2030): Past Trends, Future Projections and Implications for Care. *Palliative Medicine* 22: 33.

⁶³ National Council for Palliative Care. 2008. “Beyond the end of life care strategy,” *Inside Palliative Care*. London: NCPC, Spring 2008.

2.4 Study approach

The starting point is that patients generally prefer, as relevant surveys indicate, not to die in hospital. We set out to test the hypothesis that reductions in acute care utilisation by patients during their last year of life (either in emergency admissions or in hospital length of stay) could result in savings that could be re-deployed for patient care improvements in other settings. Thus, our study explores and provides cost estimates of decreased reliance on acute care during the last year of life.

This requires information on various relevant parameters such as evidence of the effect of palliative care both on costs and non economic outcomes and constructing a model to reflect reality and incorporate the evidence.

The study has two distinct phases. In the first phase we review and examine the end of life and palliative care literature for evidence of their effectiveness and resource consumption; in order to obtain estimates that may be relevant for the quantitative analysis. The second task is the quantitative analysis. First we estimate the current financial implications to the NHS of the current usage levels of palliative care services in England, and then we explore the amount of hospital resource consumption that could be avoided if higher levels of adoption of palliative care services were to be adopted.

Thus we built a Markov model⁶⁴ (see Chapter 4), to reflect the current situation in England for terminally ill patients and estimate the resource utilisation and costs during their last year of life. We considered patients suffering from either cancer or organ failure (heart and respiratory). Then, we used the model to simulate various scenarios reflecting greater use of palliative care for these patients during their last year of life. Chapter 3 describes the review of the literature; Chapter 4 discusses the resulting context of the modelling exercise (model description and assumptions); Chapter 5 shows the results of the analysis; and Chapter 6 discusses the findings and provides the conclusions.

⁶⁴ A Markov model is a probabilistic approach that can replace a decision tree. Markov models are excellent ways of abstracting simple concepts into a relatively easily computable form, especially given the current computation power. Its basic characteristics are the transition probabilities assigned from a particular state to another, the cycle length and the number of cycles that the model should be run.

This chapter describes the major findings from the review of the relevant literature. The aim is to identify the evidence for the effect palliative/end of life care has on outcomes, both economic and non economic, e.g. quality of life, patient satisfaction. Findings from this review will facilitate decisions about model structure, parameters and inputs for the analysis. We present first the health outcomes and then the effect of care on the economic outcomes. We relied mostly on systematic reviews to identify the parameters of interest for the former; a more systematic approach was followed for the latter.

3.1 **Evidence for the effects of palliative care on health outcomes**

The objective was to identify any evidence for the effects that the provision of palliative care services have. Mainly, these effects include amelioration of distressing symptoms and others that affect the quality of life of the patient and of their carers. These include: reduction in distressing symptoms; improved mental health of patient and carer; patient and carer satisfaction; desired place of death; quality of life/quality of death; open and honest communication as desired, and resolved communication issues; fears, grief anger^{65,66} and pain; quality of life; satisfaction; referral to other services; therapeutic interventions; and care experience, etc. We relied mostly on recent systematic reviews that examined these issues.

Over the years, the evidence on the effects of palliative care has become more conclusive, although many critical issues still lack high-quality evidence. For example, Salisbury et al. (1999) concluded that methodological weaknesses prevented any firm conclusions about the effectiveness of palliative care.⁶⁷ Reviewing 73 papers on the need for palliative care, Franks (2000) concluded that the evidence surrounding the need for palliative care is generally of poor quality and often provides conflicting evidence.⁶⁸

⁶⁵ Higginson, I. 2006. Presentation “Outcome Measurement in Palliative Care: Past, Present and Future?” In: *Outcome Measurement in Palliative Care: Beyond the NICE Guidelines*. London, NCPC, 2006. http://www.ncpc.org.uk/download/events/Outcomes/IreneHigginson_300306.pdf (accessed 31 October 2008).

⁶⁶ Higginson, I. 2004. “Clinical and organizational audit in palliative medicine.” In: Doyle D, G. Hanks, N. Cherny and K. Calman. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, pp. 185-196

⁶⁷ Salisbury, C., et al. 1999. The Impact of Different Models of Specialist Palliative Care on Patients Quality of Life: A Systematic Literature Review. *Palliative Medicine* 13: 3.

⁶⁸ Frank, P.J., et al. 2000. The Level of Need for Palliative Care: A Systematic Review of the Literature. *Palliative Medicine* 14: 93–104.

Evidence from observational studies indicates that hospice care conveys benefits, such as improvement in treatment of pain or in emotional support for decedents and their families.^{69,70,71,72,73.}

To be able to make reliable assertions based on the existing evidence, the best approach is to use systematic reviews in which a strict and consistent methodology has been followed in article selection and assessing the strength of existing evidence. There have been three systematic review studies in the past six years that examined thoroughly the effect of palliative care. These and their findings are presented below.

1. *Palliative care in hospital, hospice, at home: results from a systematic review, 2002*⁷⁴

A systematic review of the literature was undertaken to assess the effects of palliative care teams. Overall, 43 studies were identified and both a quantitative and qualitative analysis were done. The authors conclude that the data indicate small positive benefits for hospice and palliative care services and support the effectiveness of palliative care teams in the different settings with a small advantage of multidisciplinary teams over single specialist ones. The main outcomes shown to improve were pain and system control. Moreover, the change of provided treatment (from intensive to a more human approach) was also associated in a positive way.

2. *End of life Care and Outcomes. 2004*⁷⁵

The US Agency for Healthcare Research and Quality and the National Institute of Nursing Research commissioned RAND to produce an Evidence Report on a wide range of issues relating to the end of life care and outcomes by examining thoroughly and systematically the literature. The findings based on the synthesis of the relevant data (after reviewing 911 articles) were that the strongest evidence was available for:

- Cancer (a reflection of the fact of integration of palliative care and oncology);
- Satisfaction and communication, pain control, practical support and enhanced care giving;
- Cancer pain and depression treatment; and,
- Interventions for improving continuity in cancer and congestive heart failure (CHF) (notwithstanding the lack of generalisability and palliative outcomes in CHF studies).

⁶⁹ Meier, D. 2007. "Quality 101: Palliative Care and the Quality Imperative," Presentation at the Center to Advance Palliative Care, New York, April 2007.

⁷⁰ Teno, J.M., et al. 2004. Family Perspectives on End-of-Life Care at the Last Place of Care. *Journal of the American Medical Association* 291: 88.

⁷¹ Christakis, N.A. and T. J. Iwashyna. 2003. The Health Impact of Health Care on Families: A Matched Cohort Study of Hospice Use by Decedents and Mortality Outcomes in Surviving, Widowed Spouses. *Social Science & Medicine*, 57: 465.

⁷² Connor, S.R. 2007. Comparing Hospice and Non-hospice Patient Survival Among Patients Who Die Within a Three-Year Window. *Journal of Pain and Symptom Management* 33: 238.

⁷³ Miller, S.C.I., et al. 2003. Hospice Enrollment and Pain Assessment and Management in Nursing Homes. *Journal of Pain and Symptom Management*. 26: 791.

⁷⁴ Higginson, I.J., I. Finlay, D.M. Goodwin, K. Hood, A.G.K. Edwards, A.M. Cook, H-R. Douglas and C.E. Normand. 2003. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *Journal of Pain and Symptom Management* 25: 150-168.

⁷⁵ Agency for Healthcare Research and Quality Evidence. 2004. *Report/technology Assessment, Number 110. End of Life Care and Outcomes*. Rockville, US: AHRQ.

3. Evidence for improving palliative care at the end of life: A systematic review, 2008⁷⁶

In 2008, after reviewing 33 high-quality systematic reviews and 89 intervention studies, Lorenz et al. conclude that strong to moderate evidence supports palliative care interventions to improve important aspects of end of life care. They note that most research addressed populations with cancer as a primary condition. However, they do find evidence that palliative care also improves health outcomes for patients with heart failure.

Finally it is worthwhile mentioning that provision of palliative services does not seem to accelerate the rate of dying (i.e. mortality rates did not increase after establishment of the palliative care inpatient service).⁷⁷ In other words, prognosis is not affected by place of care.

3.2 Evidence on the effects of palliative care on resource utilisation

Literature search

As discussed, in the last few years several systematic literature reviews have been published in the area of palliative care. Some do make reference to resource utilisation, including Finlay et al. (2002)⁷⁸ and Lorenz et al. (2008).⁷⁹ Almost invariably, the findings in these literature surveys are phrased in very general terms. The surveys tend to report the direction of the estimated effect, not the size, with Emanuel (1996) as a notable exception.⁸⁰ Since the UK healthcare system is different from that of other countries, specifically when it comes to healthcare for the elderly,⁸¹ we primarily focus on UK-based studies. However, since the evidence base for the UK is fairly limited, we expanded our search to studies in other developed countries.

We searched the PubMed database and six health economic databases for English-language publications (January 1990 to February 2008). The health economics databases include: Tufts CEA (Cost Effectiveness Analysis) Registry, HEED (Health Economics Evaluations Database), EURONHEED (European Network of Health Economics Evaluation Databases), NHS EED (NHS Economic Evaluation Database), DARE (Database of Abstracts of Reviews of Effects) and Health Technology Assessment (HTA). Any reviews were also scanned for useful references. Search terms used were: palliative care / end of life care / hospice / home care in combination with utilisation or costs and cost analysis.⁸²

We included publications from the UK, US, Western Europe, Australia and New Zealand. We rejected:

⁷⁶ Lorenz, K., et al. 2008. Evidence for Improving Palliative Care at the End of Life: A Systematic Review. *Annals of Internal Medicine* 148: 147.

⁷⁷ Elsayem, A., et al. 2004. Palliative Care Inpatient Service in a Comprehensive Cancer Center: Clinical and Financial Outcomes. *Journal of Clinical Oncology* 22: 2008-2014.

⁷⁸ Finlay, I.G. 2002. Palliative Care in Hospital, Hospice, at Home: Results from a Systematic Review. *Annals of Oncology* 13(Suppl. 4): 257-64.

⁷⁹ Lorenz, K., et al. 2008. Evidence for Improving Palliative Care at the End of Life: A Systematic Review. *Annals of Internal Medicine* 148: 147.

⁸⁰ Emanuel, E.J. 1996. Cost Saving at the End of Life: What do the Data Show? *Journal of the American Medical Association* 275: 1907.

⁸¹ Howse, K. 2007. *Health and Social Care for Older People in the UK: a Snapshot View, Working paper 607*. Oxford: Oxford Institute of Ageing.

⁸² For example: "Palliative Care"[Mesh] AND ("utilization "[Subheading] OR "Costs and Cost Analysis"[Mesh]). Limits: Since 1 January 1990 / Humans / English language / Abstract.

- Qualitative studies, i.e. we only include studies that quantify the effects on resource utilisation;
- Studies that addressed only the structure of palliative care provided;
- Studies focusing on patients who are not terminally ill;
- Studies about perceptions of palliative care; and,
- Studies that analysed the effects of surgery, chemotherapy, radiotherapy, stents, lasers, and similar technical interventions or studies that reported only physiological, laboratory or radiological outcomes.

We characterised studies by research design quality, study population (primary condition), intervention, country and outcomes. We had two reviewers who conducted this search and selection process independently and then agreed on a common set – both using the same search criteria.

Results

The PubMed search identified 276 potentially relevant abstracts, from which we identified 20 potentially relevant articles. In addition, the search of the six health economics databases identified another 32 potentially relevant abstracts, and another 19 articles. Subtracting duplications, we reviewed 36 articles.

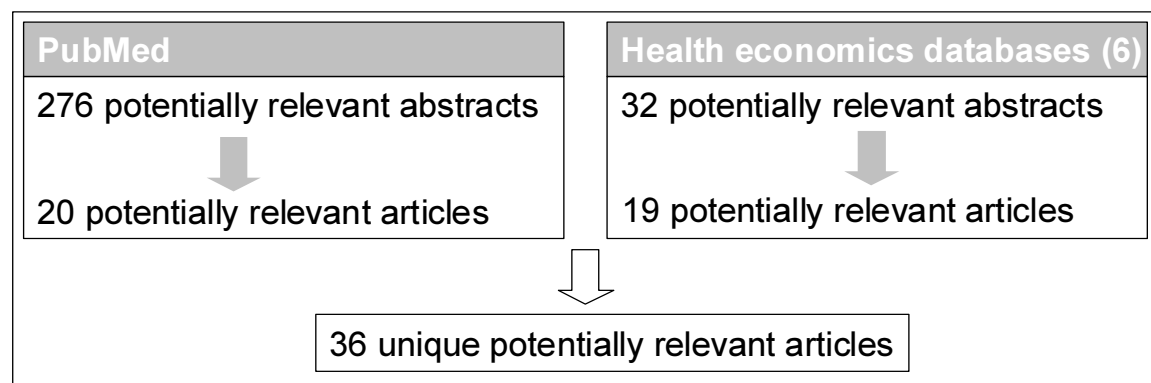


Figure 4: The search and selection process

Our review shows that the number of studies within the UK context is small. Addington-Hall et al. (1992)⁸³ and Raftery et al. (1996)⁸⁴ report the findings of a randomised controlled trial in coordination of care for cancer patients. Grande et al. (2000) evaluate the impact of a randomised control trial for hospital at home service in Cambridge, with a focus on the last two weeks of life.⁸⁵ Guest, Hart and Cookson (1998) estimate the total cost of managing terminally ill cancer patients in the UK from the time they were switched from a weak to a strong opioid until death.⁸⁶

⁸³ Addington-Hall, J.M., et al. 1992. Randomised Controlled Trial of Effects of Coordinating Care for Terminally Ill Patients. *British Medical Journal* 305: 1317.

⁸⁴ Raftery, J.P., et al. 1996. A Randomized Controlled Trial of the Cost-Effectiveness of a District Co-Ordinating Service for Terminally Ill Cancer Patients. *Palliative Medicine* 10: 151.

⁸⁵ Grande, G.E. 2000. A Randomised Controlled Trial of a Hospital at Home Service for the Terminally Ill. *Palliative Medicine* 14: 375.

⁸⁶ Guest, J.F., et al. 1998. Cost Analysis of Palliative Care for Terminally Ill Patients in the UK after Switching from Weak to Strong Opioids. *PharmacoEconomics* 14: 285.

Researchers at the Sheffield School of Health and Related Research (ScHARR) were recently commissioned to develop a model based on health economics to help support decision making on the provision of palliative care service, in support of the preparation by NICE of new national guidelines on the provision of palliative care. These investigators reported a lack of high-quality data relating to palliative care services.⁸⁷

The review of the literature and its findings are summarised and presented in Table 17 in Appendix A. Figure 5 shows a summary plot of the proportion in reductions of costs due to palliative care provision utilising the data from Table 17 with the mean of approximately 30%. This indicates that on average, studies find cost savings of close to 30% for these patients during the last year of life. This is just for indicative purposes, as a formal meta-analysis has not been carried out and differences in methodologies, context and health care system-specific were not accounted for.

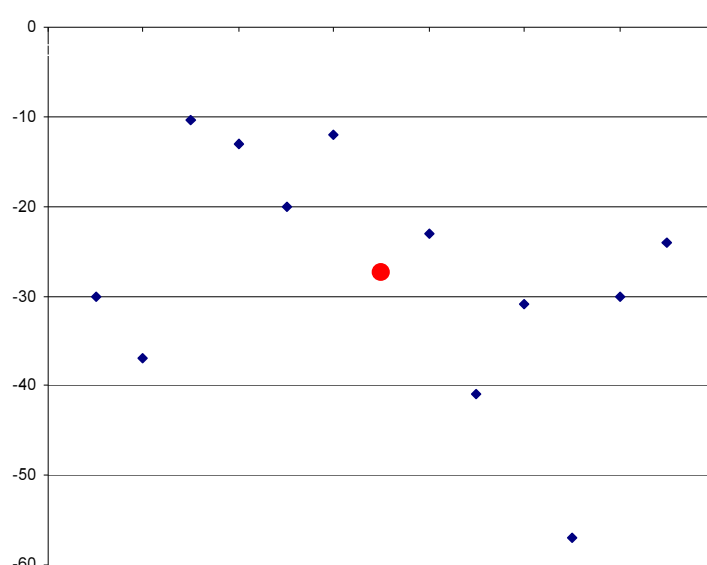


Figure 5: Average total cost savings of palliative care relative to usual care for (predominantly) cancer patients, in percent⁸⁸.

Despite the limitations, consistent savings result primarily from fewer hospitalisations and, when hospitalisation occurs, savings are from less utilisation of acute hospital care resources. The savings seem to concentrate in reduced length of stay in the intensive care unit. For other primary conditions, palliative care is generally also cost saving, but not in all cases. Especially for terminally ill who stay in a hospice for a long time, the costs may actually increase compared to standard care as certain US-based studies indicate.^{89,90,91, 92.}

⁸⁷ Ward, S., et al. 2004. *Improving supportive and palliative care for adults with cancer. Economic review*. London: National Institute for Clinical Excellence.

⁸⁸ Expenditures on palliative care net of savings on usual care (narrowly defined as hospital cost, i.e. excluding caregiver burden), unless noted otherwise.

⁸⁹ Campbell, D.E., et al. 2004. Medicare Program Expenditures Associated with Hospice Use. *Annals of Internal Medicine* 140: 269.

⁹⁰ Emanuel, E.J., et al. 2002. Managed Care, Hospice Use, Site of Death, and Medical Expenditures in the Last Year of Life. *Archives of Internal Medicine* 162: 1722.

Because many conventionally managed patients are not hospitalised until a few weeks before death, hospice patients who receive hospice services for longer than 3 months have overall costs similar to or greater than those of their conventionally managed peers. Among short-term patients, most savings from hospice derive from the reduction in use of inpatient services during the last 2 months.

There are several reasons why the costs savings of palliative care are more prevalent for cancer patients. It may be because the deterioration in functional status tends to be rapid and distinct at the very end of life – where (specialist, intensive) palliative care makes most difference. Before then, relatively low cost generalist palliative care may suffice. For other conditions, such as heart failure, functional decline is more prolonged and characterised by sudden intermittent serious exacerbations, which necessitates relatively intensive palliative care for a longer time.

Another factor may be the unpredictability of death. Organ failure tends to cause long-term lack of reserve, making the timing of death unpredictable. Faced with great uncertainty, it is more likely that more invasive medical treatment is used.

None of the studies reviewed included costs of caregivers, although support of the family is essential and should be considered an integral part of any palliative support programme.⁹³ Shifting care to the community has its costs.⁹⁴

3.3 Overall summary

Overall, the review of the literature provides evidence that palliative care can reduce the symptom burden and improve satisfaction and quality of life for patients and caregivers. With regard to economic benefits almost all studies find that palliative care is cost-saving – independent from the various types of provision, including inpatient hospice and home-based care. The evidence is most clear for cancer patients.

These findings come from a variety of studies with different designs and from all over the world. Given the purpose of the study to produce quantifiable effects of greater use of palliative care in England it has become evident that we cannot rely on the findings of the existing literature surveys alone as many parameters may not be applicable and relevant.

⁹¹ Taylor, D.H., et al. 2007. What Length of Hospice Use Maximizes Reduction in Medical Expenditures Near Death in the Us Medicare Program? *Social Science and Medicine* 65: 1466.

⁹² Chochinov, H.M. and K. Janson. 1998. Dying to Pay: the Cost of End of Life Care. *Journal of Palliative Care* 14: 5.

⁹³ Axelsson, B. and S.B. Christensen. 1998. Evaluation of a hospital-based palliative support service with particular regard to financial outcome measures. *Palliative Medicine* 12: 41.

⁹⁴ Guerriere, D.N., et al. 2008. Valuing Care Recipient and Family Caregiver Time: A Comparison of Methods. *International Journal of Technology Assessment in Health Care* 24: 52.

Almost all of the researchers in the field acknowledge the methodological difficulties in attempting to systematically and quantitatively summarise the effects of palliative care (PC) (and end of life care) in terms of its various outcomes. Overall, though, the review of the literature consistently supports the notion that PC provides benefits to those who receive it. It reduces the burden of the distressing symptoms and improves overall symptom control; furthermore it can provide satisfaction and quality of life both to patients and caregivers. For the purposes of this study we accept that the evidence is sufficient and consistent that improvements in those outcomes are associated with the provision of PC and end of life care services. Alternatively, at the very least provision of those services do not compromise outcomes compared to the more “traditional” acute care-based model. In terms of costs and resource utilisation most studies do indicate the potential of PC to be cost saving by reducing the need for hospitalisation and acute care treatments. The evidence is clearer for cancer patients and is predominantly obtained from US studies. Resource utilisation and consumption of costs, however, are health system-specific. Because the major study aim is to examine the financial implications for the NHS we use data to estimate current costs of delivering care in the last year of life (which includes current levels of hospice and community-based palliative care and acute admissions. At a second stage we model the effect that decreased utilisation of acute care would have on the NHS.

Study population: The population under study is patients in England in their last year of life suffering from either cancer or from organ failure (heart or respiratory). It is undisputable that patients with organ failure who are at the end of their life have palliative care needs as severe and distressing as those with cancer. Patients suffering from other conditions of equal importance in terms of prevalence, and economic burden, such as dementia or renal failure are also subject to end of life care services.^{95,96} We were restricted in including these patients in the analysis because of the lack of relevant information and data for modelling.

The prevalence of heart failure is likely to increase mainly for two reasons: it is a disease of the elderly and is also a sequela of acute myocardial infarction, a disease from which more

⁹⁵ Lakhani, M. 2008. *Dying well with dignity*.
<http://www.ncpc.org.uk/download/events/DyingWell/MayurLakhani/pdf> (accessed 24 October 2008).

⁹⁶ Kidney Research UK. 2007. *Chronic Kidney Disease Prevalence*,
<http://www.kidneyresearchuk.org/content/view/419/570> (accessed 3 November 2008).

people survive because of therapeutic developments. In England there are 274 heart failure cases per 100,000 people and 293 heart failure sufferers per 100,000 people with the last two stages of the disease (as classified by severity of symptoms).⁹⁷ This translates into 300,000 and 230,000 patients with definite and probable heart failure, respectively⁹⁸

In 2020 chronic obstructive pulmonary disease (COPD), is expected to be the third largest cause of mortality in the western world. Currently in the UK there are almost 900,000 patients suffering from COPD and half as many more without being diagnosed.⁹⁹ Patients dying from COPD have a heavy symptom load of both physical and psychological suffering, not only from breathlessness but also from pain and depression, with pain in particular, found to be poorly addressed.^{100,101.}

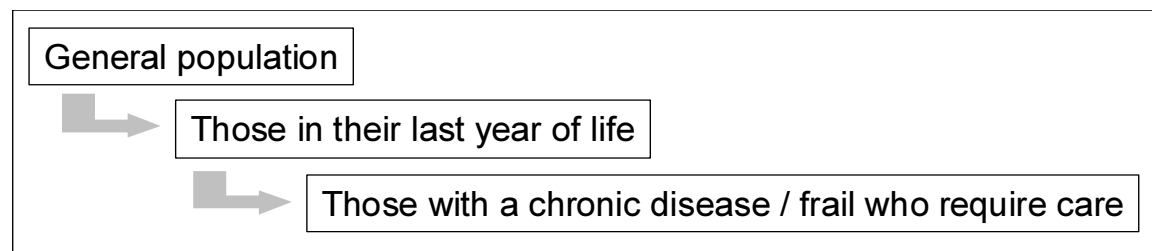


Figure 6: Population under study

We aimed to develop a model that would represent the current situation in England with regard to the provision of services for these patients in their last year of life in order to establish a baseline for the current cost of delivering care for this period. The objectives are twofold: a) to evaluate the end of life's total costs (health and social care costs); and, b) to estimate the total amount of time patients spend in each care setting. Consequently, these results were used as a basis to simulate different policy scenarios and examine the impact of different degrees of expanding the reach and availability of palliative care services and thus reducing the number of emergency admissions a patient has and/or the length of stay in acute care following an emergency admission.

⁹⁷ Beattie, J. 2005. *The Burden of Advanced Heart Failure: An Instrument to Facilitate Population Based Needs Assessment for the Provision of Palliative/Supportive Care for Management of this Chronic Progressive Disease*. London: National Health Services.

http://www.heart.nhs.uk/endoflifecare/4_setting_the_baseline/4.2_resources/Population%20based%20needs%20assessment%20tool.doc (accessed 6 October 2008)

⁹⁸ Tebbit, P. 2006. *The significance of data: Palliative & End of Life Care*. London: National Council for Palliative Care. http://www.ncpc.org/download/events/Hf_190106/Peter_Tebbit_19_01_06_HF_Event.pdf (accessed 3 November 2008).

⁹⁹ National Institute for Clinical Excellence. 2004. *Supportive and palliative care: the Manual*. London: NICE, 24 March 2004.

¹⁰⁰ Beattie, J. 2006. Presentation at "Palliative Care and Heart Failure: Moving Forward Together" London: NCPC Conference. www.ncpc.org.uk/events/pc_in_hf.html

¹⁰¹ Connolly, M. 2006. Presentation at "Palliative Care and Heart failure: Moving forward together". London, NCPC Conference. http://www.ncpc.org.uk/download/events/HF_190106/Mike_Connolly_Morning_Session_19_01_06_HF_Event.pdf (accessed 6 October 2008).

The model did not consider and therefore does not allow for issues such as potential hurdles to wider utilisation of PC services or economies of scale that can be produced.¹⁰² We also did not attempt to incorporate to the model any estimation of the carers' burden. Studies do show the significance of unpaid labour and productivity losses incurred by carers of patients. A study by Fassbender, (presented at the 5th Research Forum of European Association of Palliative Care), measured time spent by caregivers for cancer patients and estimated their time related economic losses. Caregivers provided a total of 91.6 hours of care per week with an estimated "cost" of little over £20.000 per patient.¹⁰³ For more information on published literature the reader could refer to Appendix F for a summary of selected published studies on this topic.

4.1 **Rationale and description of the model**

We used decision analytic techniques and modelling to represent the current situation in England. Decision analytic modelling allows for a rational, realistic, scientific and timely approach to measure the overall impact of healthcare policies by using the best available evidence from different sources to produce detailed estimates of the economic consequences of different healthcare interventions and policy options.

For modelling purposes, we consider current provision of care in England to entail acute care and palliative care. The model estimates the cost per average patient; a combination of patients who are receiving palliative care outside a hospital (and do not have emergency admissions), patients not receiving palliative care (and have repeat admissions), and patients who will be receiving some palliative care in the community (which is not sufficient to avoid all admissions). Acute care is the care patients in their last year of life receive with no specific/explicit consideration of palliative objectives; essentially it comprises repeated hospitalisations as their condition worsens. Thus, patients are assumed to have been treated in non-palliative inpatient hospital units. By contrast, palliative care is offered to patients either at home and in day care as part of community services, and/or in inpatient hospice units.

During their last year of life patients can receive care in different settings at different points in time. In this type of a situation, people move (transit) in and out of various settings (states). This situation can be appropriately depicted and analysed through a Markov model.¹⁰⁴ This is a technical term for modelling situations where there is a need to model transitions between different states over a specified period of time. Within a Markov model, time elapses explicitly in discrete time periods, over and over again; this discrete time period is called the model's "cycle". The overall time horizon of the study is

¹⁰² Ward, S., et al. 2004. *Improving supportive and palliative care for adults with cancer. Economic review*. London: National Institute for Clinical Excellence.

¹⁰³Fassbender, K., C. Aguilar, C. Brenneis and R. Fainsinger. 2008. "Paying to Die: The economic burden of care faced by patients and their caregivers". A plenary presentation at the 5th Research Forum of the European Association for Palliative Care (EAPC), Trondheim, Norway, 28th – 31st May 2008. Published in: *Palliative Medicine* 22(4): 400.

¹⁰⁴ Drummond, M.F., M.J. Sculpher, G.W. Torrance, B.J. O'Brien and G.L. Stoddart. 2005. *Methods for the Economic Evaluation of Health Care Programmes*. Third edition. Oxford: Oxford University Press.

comprised of the sum of these distinct time cycles. A fundamental requirement of the model is the probability of a patient occupying a given state when moving from one cycle to the other.

A Markov model is distinguished by its simplicity, its ease of use in calculating prognosis and its faithful representation of many healthcare problems.¹⁰⁵ Our study utilises a general Markov model and illustrates its application in a healthcare decision analysis with complex features. Since the focus is on population average costs this model is likely to be relatively robust in its findings.

An added flexibility of the Markov model (as opposed to the decision tree alternative) is that it is structured around mutually exclusive states. Thus, a complex forecast estimation is reflected as a set of possible transitions between the different states over the specific time horizon instead of multiple number of paths of a decision tree.

As discussed, the problem considered here is the history of the type of care cancer patients and those suffering from organ failure receive during their last year of life in England. So a hypothetical cohort of patients is followed as they journey through the system over the course of their last year of life. This can be viewed for an individual patient as a sequential progression through care settings. These care settings correspond to the Markov states of the model and are depicted in Figure 7.

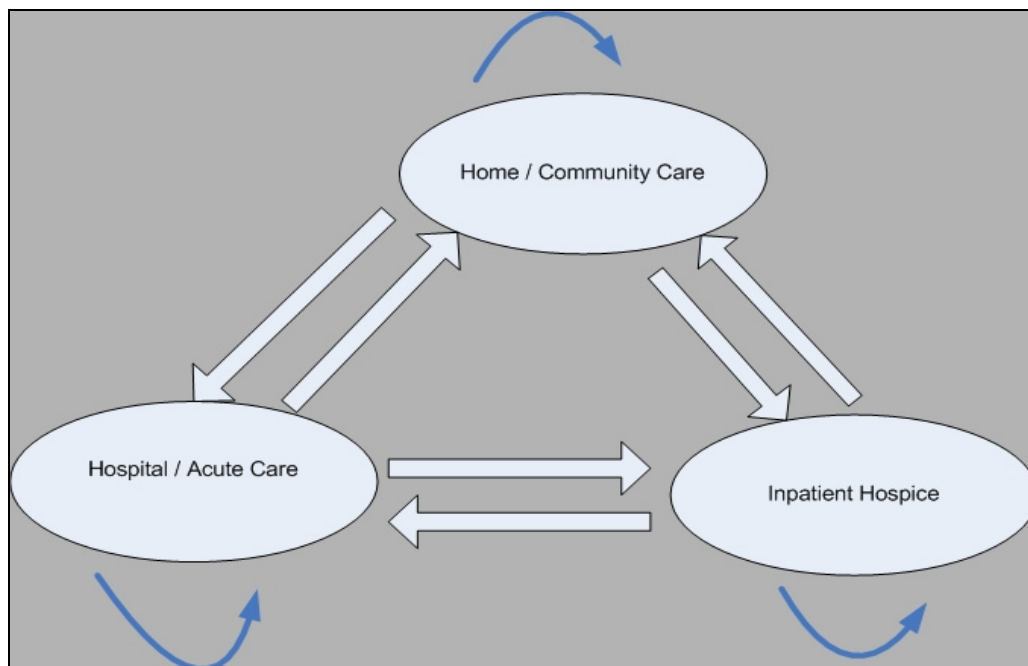


Figure 7: Transitions between the three states

¹⁰⁵ For example: Sonnenberg, F. and R. Beck. 1993. Markov Models in Medical Decision Making: A Practical Guide. *Medical Decision Making* 13: 322–338. See also, the book by A. Briggs, K. Claxton and M. Sculpher. 2006. *Decision Modelling for Health Economic Evaluation*. Oxford: Oxford University Press.

Patients enter the model from the Home/Community Care state. At any time, the patient occupies one state only. In Figure 7 this is represented as a patient being “in” one of the three ovals. The possible changes of state (settings), or *transitions*, that occur over the time cycle are illustrated as arrows. After each cycle, the patient resides once again in one of three ovals: either by continuing at the current state (represented as the small curved arrows), or by moving to another state. Thus, it is possible to leave hospital, hospice or home via a transition which has a specific probability, called a transition probability. Overall, as there are three care settings and three options at each time cycle there are nine possible transitions a patient can have.

A patient can be in one care setting only on each day and on each subsequent day they can remain in that state or move to one of the alternative states, with a specified transition probability. The time patients spend in each healthcare setting is also derived from the analysis. To reconstruct the last year of life, a patient in the model is assumed to be alive for 365 days and die on day 366. In reality of course there would be people entering and leaving the model each day. Nevertheless, the assumed “reality”, that all patients enter at the same point has no impact on the question under study, as it does not effect potential resources released or days of care avoided.

The next section presents the assumptions we had to make for model development and analysis.

4.2 **Model assumptions**

In any modelling exercise it is necessary to make certain assumptions. This facilitates model development and allows the analysis to proceed.¹⁰⁶ The assumptions we made in our study are presented below. These assumptions included the following: a) reflect fundamental characteristics of any Markov model; and, b) clarify and assist in mapping the sequence of events and outcomes under study.

Development of a Markov model dictates and requires certain assumptions. These relate to model cycles and transition probabilities.

- All patients are assumed to suffer from end of life (EOL) conditions and are in the last year of their life.
- The length of each cycle in the model is one day. At each cycle the patient can be at one stage only.
- Each patient is “alive” in the model for 365 days; death occurs for all on day 366.
- The transition probabilities are influenced only by the present state and not by the previous history. These transition probabilities are fixed for all cycles and do not change.

¹⁰⁶ See also Appendix A1, sections A1 and A3.

To be able to proceed with model development and analysis and derive model inputs a series of additional assumptions were made relating to the care provided and the way costs are estimated. More specifically, these are as follows:

- People do prefer to be cared for in the community or in a hospice and improve their experiences of care by avoiding time in hospital. This is consistent with the existing evidence;
- Interventions to reduce emergency admissions or facilitate more timely discharge (without reducing the standard of patient care) can be implemented. This has been demonstrated by Marie Curie Cancer Care and other organisations;
- A patient's life expectancy is not affected (in any direction) by the time spent or treatment given in any state. There are no available data indicating that care received in the various settings affects patient's life expectancy. If that were the case then there would be an effect on the model results;
- Hospice inpatient capacity is fixed. In reality this may not be the case since appropriate referral practices may enable hospices to take more patients. In such a case there would be more opportunities to reduce actual time spent in acute care;
- For organ failure patients we had to use lumped data based on the total number of deaths caused by the respective conditions. A linear combination was used (details in Appendix B) to calculate hospital's length of stay (LOS) and the figures for total and emergency admissions;
- Similarly, for the organ failure case, because of lack of adequate data, we used the whole hospice sample's basic characteristics to derive figures for the average hospice LOS (i.e. 12.9 days), the proportion of hospice discharges to hospital (0.056) and the proportion of hospice admissions from hospital (0.282);
- Hospice care costs do not differ between NHS-run and voluntary sector hospices. There are no available data to indicate otherwise. If differences exist, they could potentially influence the results depending on the direction of the evidence. If it were less expensive to provide care in a NHS hospice than a voluntary one then we would expect a slight decrease in the baseline cost estimates. The potential resources available though from redistribution in each scenario would not be affected;
- All home care service costs are met by the taxpayer. This may not be the case as some of these services may be subsidised. There is no specific evidence to calculate a proportion that can be attributed to subsidies. In any event, this leads to an underestimation of the potential level of resources available for reallocation;
- The cost of delivering end of life care at the community setting does not differ between residential care and home care. Even in the case that the cost in residential care is higher, a significant effect is not expected as the proportion of patients with the conditions under study that die in residential care is very small. The final result would be a small underestimation of the potential resources available for redistribution; and,

- Finally, we had to make a major assumption to allow the calculation of the potential benefits for patients suffering from organ failure. We assumed that the cost of delivering end of life care in all the settings for those patients is similar to the costs incurred by cancer patients. This is not likely to be the case though as organ failure patients have different care needs and receive different types of interventions. Indeed there is some evidence suggesting that care for COPD patients is likely to be more expensive than this for lung cancer.¹⁰⁷ The assumption was made though, because there is lack of actual costing/expenditure data for the organ failure patients. Thus, in the absence of more accurate data, the direction of the effect on the results is not clearly evident.

¹⁰⁷ Brunnhuber, K., S. Nash, D. E. Meier, D. E. Weissman and J. Woodcock. Spring 2008. *Putting evidence into practice: Palliative care*. British Medical Journal Publishing group.

4.3 Data sources

The model structure requires two main data inputs to allow it to run: namely, a) the transition probabilities; and, b) the costs associated with each care setting. To calculate the transition probabilities, (a rather complex task since there are nine potential transitions in total), a combination of data obtained from various sources was used. These sources are: the Office of National Statistics (ONS), the Hospital Episode Statistics (HES) data and the Minimum Data Set (MDS) of the National Council of Palliative Care (NCPC).¹⁰⁸

Data on the cost of a day of care in hospital, hospice and the home/community care setting is also available.¹⁰⁹ These data combined with the time spent in each state and the numbers of patients (cohort) who die of the condition being modelled allow us to estimate the overall cost of care for the last year of life.

4.4 Calculating transition probabilities

One of the issues that had to be resolved to make the calculations possible was to determine the *average* rates of transition of patients between hospital, hospice and home. These rates were calculated using data from HES and the MDS.^{110,111} The objective is to determine the proportions of patients in each of the three locations who would be “discharged” from each state, on an average day, and following this, where they would go. Once these transition rates had been calculated, the average numbers in hospital, hospice and home on any given day can be determined.

The calculations were not simple, because the data available did not translate directly to transition rates. Nevertheless, it was possible to make the calculations to a level of accuracy consistent with the data to derive the transition rates and average numbers, which could be used in cost calculations. The methods used for these calculations are set out in Appendix B, sections B.3, B.4 and B.5.

Appendix B gives a detailed description of the sources, the detailed methodology and technical details for estimating the required model inputs.

4.5 Sensitivity analysis

The inherent uncertainty contained in the model parameters was addressed by conducting a series of sensitivity analyses. We have applied univariate (one-way) sensitivity analysis: the impact on the results of changing the value of one parameter at a time while keeping the

¹⁰⁸ See Appendix B, section B.2: Table 18.

¹⁰⁹ See Appendix B, section B.6.

¹¹⁰ National Council for Palliative Care. 2007. *National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set (MDS) Full Report for the year 2006-2007*. London: NCPC, December 2007

¹¹¹ Hospital Episode Statistics (HES) as stored by the Dr Foster Unit of Imperial College, London. The data used includes admissions over a three year period from 1 April 2003 to 31 March 2006.

values of all other parameters unchanged (*ceteris paribus*). The results are shown in comparative tables and graphically in tornado diagrams. A range of alternative values were developed in close collaboration with the NAO and then tested for their impact on the baseline case estimates.

We examined the effect of changing several different model parameters, including:

- For hospice care: the patients' mean length of stay, the total inpatient admissions to hospice, the proportion of hospice patients per case (cancer/organ failure) and the proportion of hospice admissions in the last year of life;
- For hospital care: emergency hospital admissions per patient and the elective hospital admissions per patient; and,
- Healthcare costs per day for each of the different settings, costs for Home/Community Care, Hospital and Hospice.

The previous chapter introduced the modelling methodology and the general framework of the analysis. This chapter presents the results of the analysis. We estimate total costs of care provided to patients in their last year of life, along with the number of days patients spend on average in each setting (hospital, hospice and home/community care) for both cancer and organ failure. Sensitivity analysis indicates the most critical parameters, and finally different scenarios are simulated to introduce the potential financial consequences of end of life care expansion in England. We analyse the Markov model by following a hypothetical cohort of patients through their last year of their life. We use the actual number of deaths from the respective conditions in England in 2006 and the patients that utilised inpatient hospice services shown in Table 2, to estimate the total costs. The chapter is structured into three subsections: section 5.1 presenting the results for cancer patients, section 5.2 with the results for organ failure patients and section 5.3 that discusses certain limitations related to the model assumptions and data. Subsections 5.1 and 5.2 are further divided by presenting first the baseline analysis, then the sensitivity analysis results and finally the simulation effects of the different scenarios.

All calculations were carried out with the specialised decision analytic software TreeAge Pro 2008 Suite (Release 1.3.1). The HES data is based on the 2005/06 financial year, whilst the ONS data is for the 2006 calendar year. MDS is for the period 2006/07.

Table 2: Cohort numbers considered in the Markov modelling exercise

Observation	Cancer patients	Organ failure patients
Whole cohort	126,779	29,440
Total Hospice patients: 43,050	39,907	205 (proxy: number of deaths)

5.1 Results for end of life cancer patients

5.1.1 Baseline analysis

The cohort of patients was assumed to enter the model at the home/community care setting and following the underlying assumptions of the model tracked through the year until the last day of their life. The results in terms of cost and days spent in each setting are shown in Table 3 below.

Table 3: Baseline Markov model results for cancer patients over the last year of their life

Total costs for the whole cohort	Overall average unit costs per cancer patient	Setting	Total days in setting (per cancer patient)	Average unit costs per patient (setting specific)
£1.805 billion	£14,236	Hospital	17.3 days	£4,128
		Hospice	3.5 days	£464
		Home	344.2 days	£9,644

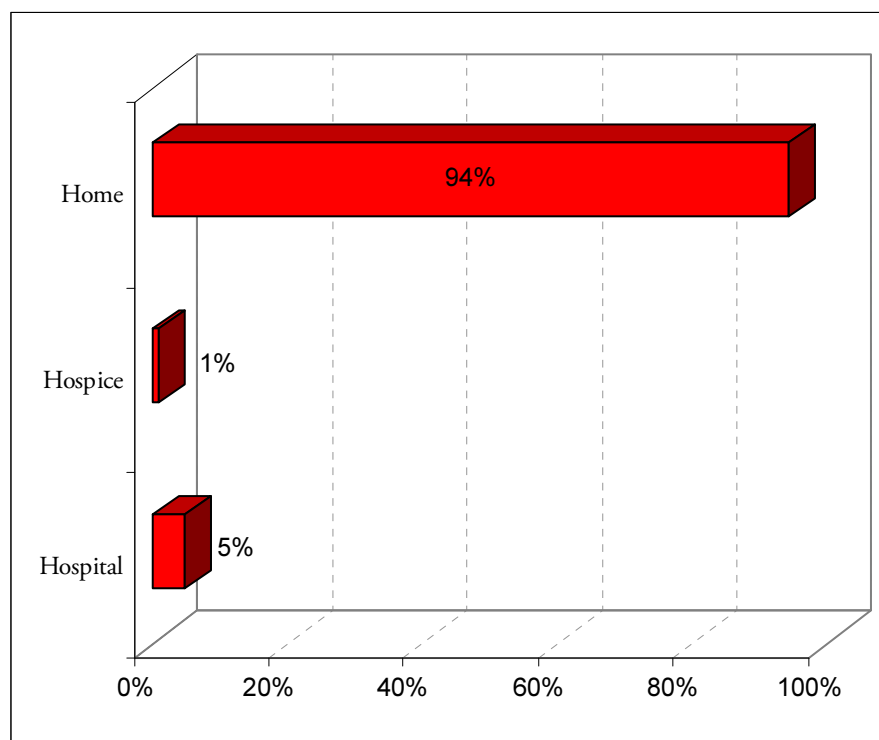


Figure 8: Amount of time spent in each setting by the "average" cancer patient in the last year of life

We estimate that the cost of providing EOL-care for the last 365 days of life to cancer patients is approximately £1.805 billion. This figure is based on the accumulated cost of care being provided in hospital, hospice and home/community care settings for the circa 126,779 people who die from cancer annually. This amounts to £14,236 per patient.

Cancer patients who died in 2005/06 spent 344.2 days at home/community care, 17.3 days in hospital and 3.5 days in a hospice in the year prior to death. Note that these averages mask the fact that relatively few patients account for the majority of days spent in hospice (i.e. although the average number of days in the hospice per hospice patient is 12.9 days, if this figure is spread across the whole cohort it goes down to 3.5; this is due to the fact that not all patients spend time in a hospice during their last year of life).

5.1.2 Sensitivity analysis

The inputs to the model are subject to some degree of uncertainty and hence sensitivity analysis was warranted.

The following parameters were investigated via a one way sensitivity analysis:

- For hospice care: the patients' mean length of stay, the total inpatient admissions to hospice, the proportion of hospice patients per case (cancer/organ failure) and the proportion of hospice admissions in last year of life;
- For hospital care: emergency hospital admissions per patient and the elective hospital admissions per patient; and,
- Healthcare costs per day for each of the different settings, costs for home/community care, hospital and hospice.

The ranges investigated are given in Table 4. The methodology followed consisted of two steps, as follows:

- Step 1. Calculation of the transition probabilities corresponding to the particular parameters; and,
- Step 2. Calculation of the total cost of delivering end of life care in the last year of life.

Table 4: Summary of parameters under sensitivity analysis for the cancer model

Block of variables	Range	Description
Hospice	[11.9–13.9]	Average length of stay in hospice: 12.9 ± 1.0
	[42351–43568]	Inpatient admissions to hospice: $43050 \pm 5\%$
	[0.88065–0.97335]	Proportion of hospice cancer patients: $92.7\% \pm 5\%$
	[0.70–1.0]	Proportion of hospice admissions in last year of life
Hospital	[1.57–1.67]	Admissions to hospital per patient (elective $\pm 10\%$)
	[1.008–1.232]	Emergency hospital admissions per patient $\pm 10\%$
Costs	£25.22–£30.82	Home/community care cost per day: $\text{£}28.02 \pm 10\%$
	£199.82–£244.22	Hospital cost per day: $\text{£}222.016 \pm 10\%$
	£119.23–£145.73	Hospice cost per day: $\text{£}132.479 \pm 10\%$

We chose to vary most of the variables by 10% (however, in a few cases where the evidence base was clearer or less ambiguous we opted for 5%). For most of the variables in the cancer model a maximum level of 10% uncertainty is reasonable and can be justified. For instance, the cost data is the best available; however, most but not all of the patients in the surveys suffered from cancer and the cost for non-cancer patients might be slightly different. In addition because from the Coyle et al. (1999) paper it is impossible to calculate an average life expectancy for the patients in the survey (as there is no upper limit on prognosis, just more than 1 year) there is some uncertainty about whether these costs are applicable to a whole year.¹¹² The data from the NCPC survey is around 90% complete

¹¹² If for community patients we take the mid point of the two prognosis ranges given (i.e. less than 6 months = 3 months and 6–12 months = 9 months) and assume that the average prognosis for >1 year is 15 months then the average prognosis is for 11.1 months. The average prognosis for > 1 year would only have to be 16.5 months for the average prognosis or all patients to be 1 year. On this basis it seems justified to use the figure

so numbers of patients average length of stay etc is unlikely to vary significantly in the non-responding population and so 10% is reasonable.

The sensitivity analysis results for the **hospice-related variables** are shown in Table 5.

Table 5: Summary results of total costs under sensitivity analysis of hospice parameters for the cancer model

Variable	Baseline value	Degree of variation	Effect on baseline value of £1,805 million
Average length of stay	12.9 days	± 1 day	± £3 million
Total hospice patients	43,050 patients	± 5%	± £1 million
Proportion of hospice patients with cancer	92.7%	± 5%	± £2 million
% of hospice admissions in last year of life	90%	70–100%	± £10 million, or more precise: (£1,795–1,810 million).

There is relatively low variation in the overall cost due to the fact that patients spend relatively few days in the hospice setting. The highest variation of total costs is observed as a result in varying the proportion of hospice admissions in last year of life (some ±£10 million). Note that this is the only asymmetric interval, since a proportion cannot exceed the value of 1).

The results for the **hospital-related variables** are shown in Table 6.

Table 6: Summary results of total costs under sensitivity analysis of hospital admissions for the cancer model

Variable	Baseline value	Degree of variation	Effect on baseline value of £1,805 million
Emergency admissions	1.12 admissions	± 10% (1.008–1.232)	± £33 million
Total admissions (elective admissions)	1.62 admissions	± 10% (1.570–1.670)	± £13 million

It is clear that the emergency admissions have a higher impact on the overall cost (order of magnitude of approximately ±£33 million). This is illustrated in Figure 9 below.

proposed by Coyle et al. (1999) as the cost per day of receiving care in the community setting. If you take 15 months to be the average life expectancy for an inpatient with a prognosis > 1 year then the average prognosis for all patients is just 7.5 months and those with a prognosis of > than 1 year would have to live for 32 months for the prognosis for all patients to be 12 months. However, since we know the amount of time patients do spend in hospital in the last year of life the fact that costs cover a shorter period does not seem to be source of material error in the model.

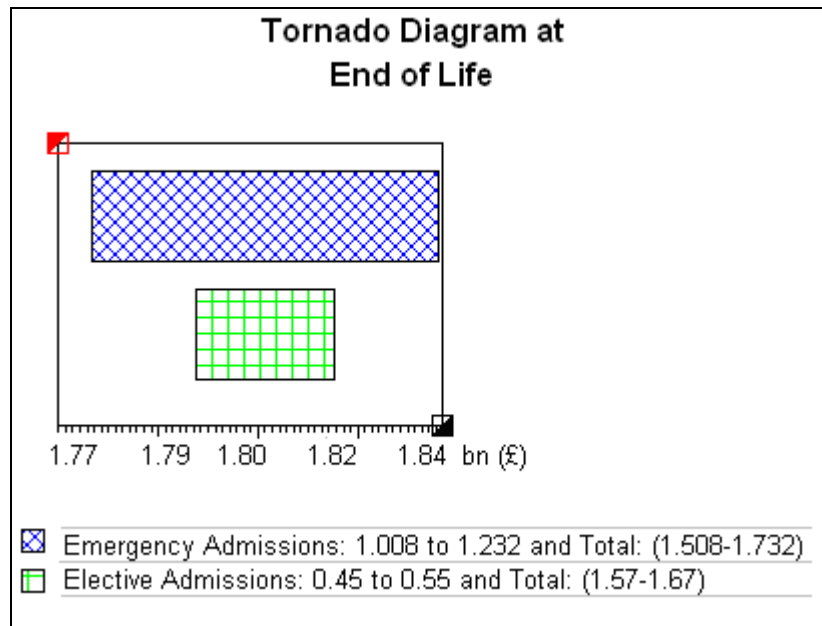


Figure 9: Tornado plot of the variation in total cost (in billions of £) of delivering end of life care to cancer patients in the last year of life (as a result of the sensitivity analysis of hospital admissions)

Tornado diagrams are very useful for sensitivity analysis (i.e. to compare the relative importance of variables). The variable under sensitivity analysis is modelled as an uncertain parameter while all other variables are held at baseline values (fixed).

Finally, the sensitivity analysis results for the **costs-related variables** are shown in Table 7.

Table 7: Summary results of total costs under sensitivity analysis of care costs for the cancer model

Variable	Baseline value per day of care	Degree of variation	Effect on baseline value of £1,805 million
Home/community care costs	£28.02	± 10% (£25.22–£30.82)	± £122 million
Hospital costs	£222.016	± 10% (£199.82–£244.22)	± £49 million
Hospice costs	£132.479	± 10% (£119.23–£145.73)	± £6 million

It becomes evident that varying the cost of home/community care has the highest impact on the overall cost. This is illustrated in Figure 10.

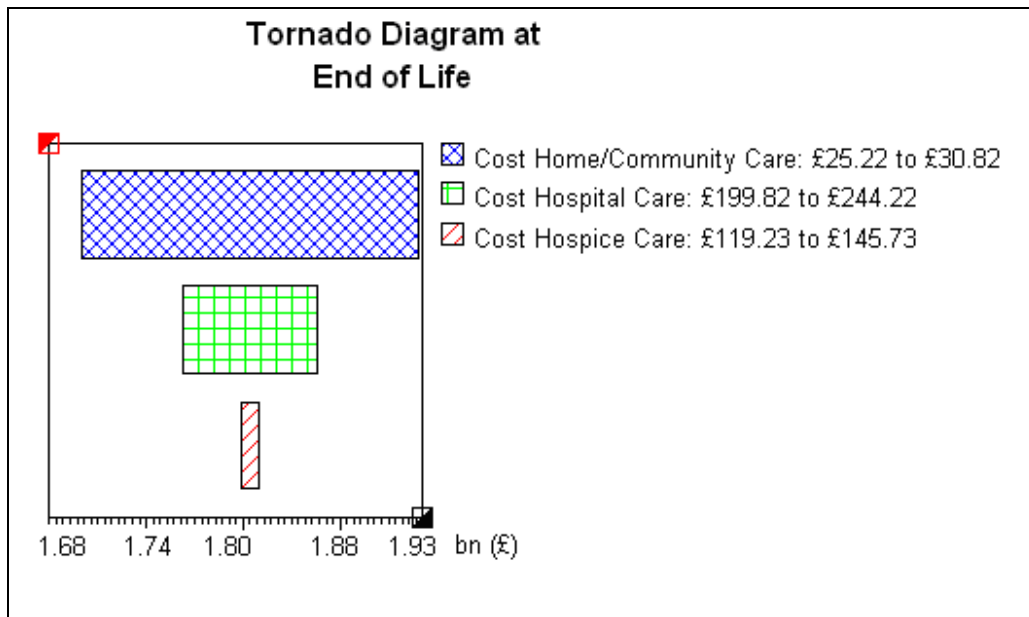


Figure 10: Tornado plot of the variation in total cost (in billions of £) of delivering end of life care to cancer patients in the last year of life (as a result of the sensitivity analysis of costs)

Comparing Table 5, Table 6, and Table 7 we deduce that varying the cost of home/community care has the biggest effect on the overall cost of delivering care in the last year of life for cancer patients. Despite being the less expensive form of care, this is where patients spend the majority of their time. A 10% decrease in the average cost of delivering community care could produce a £122 million reduction in the overall cost.

In summary, the total variation in the cancer patients' cohort estimate shown by the sensitivity analysis is in the range £1.683–1.927 billion, i.e. the cost of caring for cancer patients in the last year of life is estimated between £1.683 billion and £1.927 billion.

5.1.3 Examining different scenarios

The underlying hypothesis is that expanded use of home/community care for patients during their last year of life will result in reducing hospital acute care; this may be either the number of admissions and/or the length of hospitalisation. Once the baseline case has been established and estimates of the current economic impact of delivering care in the last year of life for cancer patients are available, hypothetical reductions to the model's inputs can be made to examine what effect these reductions have on the outputs of interest; cost of care and number of days spent in acute care. We simulated the effects of decreased hospital use. We assumed that the amount of time patients spend in acute care/hospital could be decreased by either:

- reducing the mean number of days spent in hospital following an admission (average length of stay), or
- by decreasing the number of unplanned admissions (i.e. emergency admissions).

More specifically, we investigated the effects on the average EOL costs given the following assumptions/variations in the model:

- A reduction in 1, 3 or 5 hospital days in the mean hospital length of stay (LOS) as compared to the baseline. These reductions in days can be considered as being applied to those admissions that were associated with an emergency (unplanned) admission; and,
- A reduction of 5%, 10%, 15% or 20% in emergency (unplanned) hospital admissions as compared to the baseline.

We recall that the baseline total costs for cancer are **£1,805 million** and that the baseline acute care (hospital) days amount to **17.3 days**.

The results regarding potential reductions in costs are presented in Table 8.

Table 8: Potential release of resources compared to the baseline (quoted in £m, million) for the entire cohort of cancer patients)

Reduction in % of emergency admissions	Reduction in mean LOS (days)			
	0	1	3	5
0	0	£26m	£78m	£132m
5%	£16m	£42m	£91m	£141m
10%	£33m	£56m	£104m	£151m
15%	£49m	£71m	£117m	£161m
20%	£66m	£87m	£129m	£171m

As Table 8 shows, on average a 3-day reduction in the mean hospital LOS, combined with a 10% reduction in emergency admissions implies some £104 million reduction in the total end of life cost.

The results regarding days of acute care avoided compared to the baseline (=17.3 days) are shown in Table 9.

Table 9: Days of acute care avoided in comparison to the baseline (per cancer patient)

Reduction in % of emergency admissions	Reduction in mean LOS (number of days)			
	0	1	3	5
0	0	1.1	3.2	5.4
5%	0.6	1.6	3.6	5.7
10%	1.2	2.1	4.1	6.0
15%	1.8	2.7	4.5	6.4
20%	2.4	3.3	5.0	6.7

We observe that, a 10% reduction in emergency admissions combined with a 3-day reduction in mean LOS per emergency admission in hospital would reduce by 4.1 days the acute care provision.

5.2 Results for end of life organ failure patients

5.2.1 Baseline analysis

A similar analysis to that conducted for cancer patients was conducted for patients suffering from heart and respiratory organ failure during their last year of life. It should be noted that data availability and quality for those conditions were not as adequate and appropriate as for cancer patients. Certain assumptions had to be made to proceed with the analysis (see Appendix B, section B.3); hence the results should be viewed with caution and only for indicative purposes as accuracy may have been jeopardised.

The results are shown in Table 10.

Table 10: Baseline Markov model results for organ failure patients over the last year of their life

Total costs for the whole cohort	Overall unit costs per organ failure patient	Setting	Total number of days per setting and patient and per organ failure patient	Unit costs per day per setting
£553 million	£18,771	Hospital	40.2 days	£9,665
		Hospice	0.1 day	£8
		Home	324.7 days	£9,098

5.2.2 Sensitivity analysis

The parameters' ranges to be investigated via a one-way sensitivity analysis are given in Table 11.

Table 11: Summary of parameters used in the sensitivity analysis of the organ failure model

Block of variables	Range	Description
Hospice	[11.9–13.9]	Average length of stay in hospice: 12.9 ± 1.0
	[38,745–47,355]	Organ failure inpatient admissions to hospice: 43,050±10%
	[0.004765–0.00953]	Proportion of hospice patients with cancer: 0.4765%±100%
	[0.70–1.0]	Proportion of hospice admissions in last year of life
Hospital	[3.049–3.075]	Admissions to hospital per patient (elective ± 10%)
	[2.769–3.355]	Emergency hospital admissions per patient ± 10%
Costs	£22.42–£33.62	Home/community care cost per day: £28.02±20%
	£177.62–£266.42	Hospital cost per day: £222.016±20%
	£105.98–£158.98	Hospice cost per day: £132.479±20%

The sensitivity analysis results for the **hospice-related variables** are given in table 12.

Table 12: Summary results of total costs under sensitivity analysis of hospice parameters for the organ failure model

Variable	Baseline value	Degree of variation	Effect on baseline value of £553 million
Average length of stay	12.9 days	± 1 day	± £0 million
Total hospice patients	43,050 patients	± 10%	± £0 million
Proportion of hospice patients with cancer	0.4765%	+ 100%	± £0 million
% of hospice admissions in last year of life	90%	70%–100%	± £0 million.

As seen in Table 12 there is hardly any variation in the overall cost due to the fact that there are an extremely small number of days spent in hospices. The highest variation of total costs that is observed for all cases is less than a £1 million. As an exploratory analysis we have considered the possibility of all non-cancer inpatient hospice patients to be organ failure patients (i.e. 7.3%). In this particular case the cost variation was less than £3 million.

The sensitivity analysis results for the **hospital-related variables** are as follows:

Table 13: Summary results of total costs under sensitivity analysis of hospital admissions for the organ failure model

Variable	Baseline value	Degree of variation	Effect on baseline value of £553 million
Emergency admissions	2.929	± 10% (2.769-3.355)	± £25 million
Total admissions (elective admissions)	3.062	± 10% (3.049-3.075)	± £2 million

From Table 13 it is clear that the emergency admissions have a higher impact on the overall cost (order of magnitude of approximately ±£25 million).

Finally, the sensitivity analysis results for the **cost-related parameters** are as follows:

Table 14: Summary results of total costs under sensitivity analysis of care costs for the organ failure model.

Variable	Baseline value	Degree of variation	Effect on baseline value of £553 million
Home/community care costs	£28.02	± 20% (£22.42–£33.62)	± £54 million
Hospital costs	£222.016	± 20% (£177.62–£266.42)	± £53 million
Hospice costs	£132.479	± 20% (£105.98–£158.98)	± £0 million

Table 14 shows that varying the home/community care cost has the highest impact on the overall cost (but only marginally as compared to the hospital care). This is also illustrated in Figure 11.

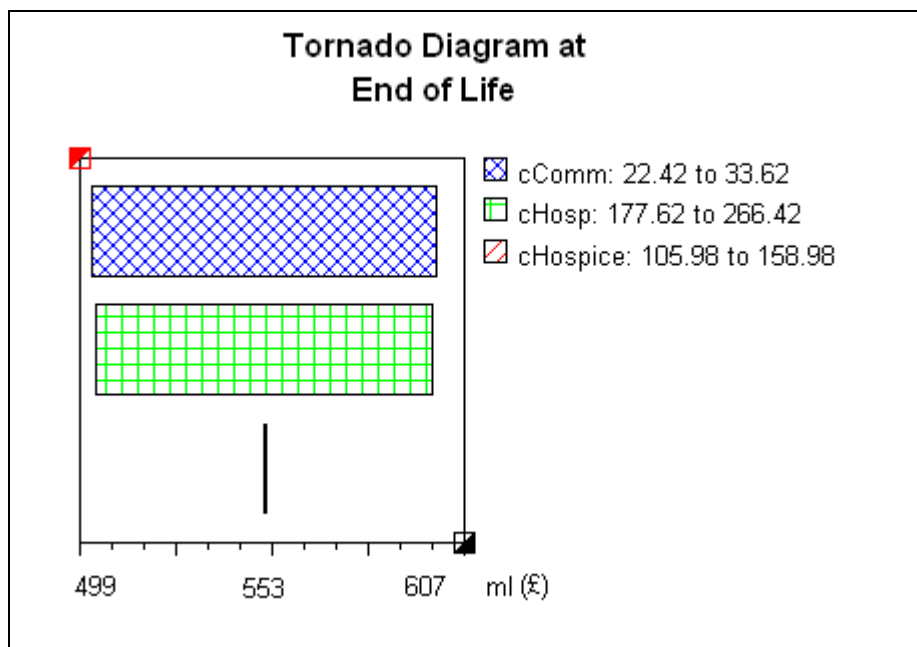


Figure 11: Tornado plot of the variation in total cost (in billions of £) of delivering end of life care to organ failure patients in the last year of life (as a result of the sensitivity analysis of costs)

Comparing Table 12, Table 13 and Table 14, we deduce that varying the home/community care and hospital costs has the biggest effect on the overall cost of delivering care in the last year of life for organ failure patients. This is important given the existing uncertainty over robust cost estimates for these conditions. A 20% decrease in the average cost of delivering home/community care (or hospital) care could produce a £54 million (or £53 million) reduction in the total costs for the whole cohort.

In summary, the total variation in the organ failure patients' cohort estimate shown by the sensitivity analysis is in the range £499–607 million; i.e. the cost of caring for organ failure patients in the last year of life is estimated between £499 million and £607 million.

5.2.3 Examining different scenarios

As discussed earlier for the cancer model, once the baseline case has been established and estimates of the current economic impact of delivering care in the last year of life for organ failure patients are available, hypothetical reductions to the model's inputs can be made to examine what effect these reductions have on the outputs of interest: cost of care and number of days spent in acute care.

More specifically, we investigated the effects on the average EOL costs given the following assumptions/variations in the model:

- A reduction in 1, 3 or 5 hospital days in the mean hospital LOS as compared to the baseline. These reductions in days can be considered as being applied to those admissions that were associated with an emergency admission; and,
- A reduction of 5%, 10%, 15% or 20% in emergency hospital admissions as compared to the baseline.

We recall that the baseline total costs are **£553 million** and that the baseline acute care (hospital) days amount to **40.2** days.

The results regarding costs are presented in Table 15.

Table 15: Potential release of resources compared to the baseline (quoted in million of £ as £m) for the entire cohort of organ failure patients)

Reduction in % of emergency admissions	Reduction in mean LOS (number of days)			
	0	1	3	5
0	0	£16m	£48m	£80m
5%	£13m	£28m	£57m	£88m
10%	£25m	£39m	£67m	£96m
15%	£37m	£50m	£77m	£104m
20%	£49m	£61m	£87m	£112m

That is, for the baseline case (home/community care package with median costs) we show that on average a 10% reduction in emergency admissions combined with a 3-day reduction in mean LOS per emergency admission in hospital would release some £67 million of funds.

The results regarding days of acute care avoided compared to the baseline (40.2 days) are shown in Table 16.

Table 16: Days of acute care avoided in comparison to the baseline (per organ failure patient)

Reduction in % of emergency admissions	Reduction in mean LOS (number of days)			
	0	1	3	5
0	0	2.7	8.3	13.9
5%	1.9	4.5	9.8	15.1
10%	3.8	6.3	11.3	16.3
15%	5.8	8.1	12.8	17.6
20%	7.7	9.9	14.3	18.8

We observe that, for instance, a 10% reduction in emergency admissions combined with a 3-day reduction in mean LOS per emergency admission in hospital would reduce by 11.3 days the acute care provision.

5.3 Model limitations

There are certain limitations inherent in this analysis reflecting data limitations and model structure constraints. These are summarised below as follows:

- The model does not consider informal carer costs; it only estimates costs from the perspective of the taxpayer. This in fact may overestimate cost benefits if substantial portion of care delivery is done by carers;
- The model does not consider the impact of those patients that are admitted to the hospital from their own homes but are discharged to some form of residential care. Indeed there are a proportion of patients who remain at the hospital for longer time periods because they either cannot support themselves or are reluctant to enter a care home. There are no data available on this type of patients. This not expected though to impact the model findings as any reduced utilisation of hospital care will free up resources as other forms of care are less expensive;
- The model assumes that the amount of time patients spent in a hospice is not influenced by the number of prior emergency admissions or the average length of stay. This is a consequence of the rather limited data we had to use to derive the transition probabilities. It may result in an overestimation of the economic benefits if the assumed reductions in hospital utilisations are contingent on expansion of hospice inpatient activities;
- The model is appropriate in reflecting a patient cohort history rather than an individual patient case history. This is relevant and appropriate since the taxpayers' perspective is considered in the analysis and does not have an impact on the final outcomes;
- The model cannot and does not account for the fact that towards the end of life, periods of hospital and hospice admissions are often clustered. It does not nor is it able to predict the place of death. What it does is to estimate the resources consumed during the last year of life and calculate the amount of time in hospital care that could be avoided; and,

- We used “reasonable” assumptions on the potential of home and community end of life services to reduce emergency admissions. We were not able to locate robust and solid evidence of that effect. There is some indirect evidence indicating that community services (targeted to older people), can reduce admissions and lengths of hospital stay.¹¹³

Overall, we believe that these limitations do not alter or distort the direction or the order of magnitude of the results (especially with regards to the cancer patients). What is important is to acknowledge and be aware of them and appropriately frame any results and inferences made from the analysis.

¹¹³ Windle, K., Wagland R., Lord K., et al. 2008. *National evaluation of Partnerships for Older People Projects: Interim Report of Progress*. University of Kent: Personal Social Services Research Unit.

The NAO commissioned and worked with RAND Europe to develop a model that will allow estimation of the healthcare costs of patients during their last year of life and explore the potential for a more integrated approach to palliative care and its services. Indeed, this is a pertinent and timely policy issue. A transformation of the population's health needs and an increasing disease burden along with demographic pressures dictate a renewed consideration of alternative ways to provide care. For those patients who are suffering from terminal illness and are approaching the end of their life, there is the additional dimension of the setting where they wish to receive care and die. There is sufficient evidence to document an existing gap between patients' expressed wishes about where they should be cared for and die and what actually happens in practice.

The objective of our study was to explore and provide estimates of the financial consequences of the following: a) healthcare provision to patients during their last year of life reflecting the current situation in England; and, b) decreased utilisation of acute care. We wanted to test the hypothesis that reductions in acute care utilisation by these patients (either in emergency admissions or in hospital length of stay) could result in parallel reductions of healthcare expenditures. In close cooperation with the NAO, after having reviewed the end of life and palliative care literature for evidence of effectiveness and resource consumption, we developed a quantitative model that examines the natural history of patients (suffering from cancer and organ failure), in their last year of life in terms of the settings where they receive care. This model allows derivation of estimates for the overall time spent per healthcare setting and for the associated costs. Consequently, we used the model to simulate different scenarios reflecting different levels of palliative care and examine the cost implications.

The model we have built is a Markov model. This type of model is suitable for abstracting simple concepts/events of a recurring nature into a relatively easily computable form, capitalising current computation power. Its basic characteristics are the different states that a patient can be in (healthcare setting: "hospital", "hospice" and "home/community care"), the probability that a transition may occur from one setting to another, the discrete time, i.e. cycle length that is the unit for the analysis (we used one day) and the duration of the analysis, 365 days in our case. We chose to use a Markov model (instead of a simpler decision tree or a more complex simulation model) in order to improve transparency and interpretability. We used data from a variety of sources, predominantly from the national Hospital Episode Statistics and the National Council for Palliative Care's Minimum Data Set, and certain published studies.

The main findings can be summarised as follows:

- Overall, the total costs of caring for cancer patients during the last year of their life are approximately £1.8 billion, which corresponds to £14,236 per each patient who died in England in 2006. Respective estimates, albeit less robust, for organ failure patients are £553 million and £18,771;
- Time spent in acute care (hospital) amounts to 17.3 days for cancer and 40.2 for organ failure;
- Sensitivity analyses of the baseline estimates indicate that the most critical parameters are home/community care costs for cancer patients. Thus, while varying a range of parameters indicates consequences of around £2 million to £49 million, the impact of the cost of providing care in a home/community setting is the most critical as a variation of 10% can decrease or increase the total costs by £122 million;
- For organ failure, the variables most sensitive to uncertainty is the cost of providing home/community and hospital care where a 20% variation impacts total cost by £54 million and £53 million, respectively;
- Simulation of various scenarios that decrease the proportion of unplanned (emergency) hospital admissions or the length of stay strongly indicates the significant potential for reducing acute care healthcare expenditures. For example, a 10% reduction in unplanned admissions combined with a 3-day reduction in the length of stay could result in £104 million that could potentially be avoided in 1 year from hospital expenditures associated with the care of cancer patients during the last year of their life; and,
- Results for organ failure patients could be made robust and accurate by relying less on assumptions and by improving the availability of relevant data.

As for any modelling exercise and economic analysis that attempt to reflect reality while having to rely on existing data, there are some clear limitations in our study. This Markov model is a step forward in mapping complex human choices and their implications. It is also a simplification of reality and subject to the perennial trade-offs between data availability and complex model structure. Therefore, the study limitations are related to some of the assumptions we had to make in constructing the model and the data that are used to derive probabilities and costs. We discussed these at the end of Chapter 5. Overall, we attempted to err on the conservative side; nevertheless, there are three issues we would like to point out and acknowledge. One relates to the conditions we examined, cancer and organ failure. It is important to distinguish and note the confidence in the results. The analysis for cancer is based on solid data and evidence. Good quality data for COPD and heart failure, in particular for the associated costs both for hospital and palliative care, are not available, so we had to assume that the costs are similar to those incurred by the cancer patients; hence the results should be viewed with caution as they are more theoretical. Another related issue is the assumption we made regarding palliative care costs. We used the data from the study by Coyle et al that provides estimates for a follow-up of 6 months. We assumed that this cost estimate is proportional to the costs occurring during the last year of life. If we look at the average prognosis of community care patients in Table 1 and

assume that > 12 months could equal 15 months then the predicted life expectancy of these patients is close to 1 year. This means there is a strong case for saying the community costs used are applicable to the entire last year of life. The prognosis for the inpatients is much shorter but since we know the amount of time a patient spends as an inpatient in the last year of life this seems less relevant. Finally, we did not make any attempt to estimate the financial burden imposed on the caregivers as the perspective of the analysis was that of the NHS.

Overall, our results are consistent with evidence from the literature on the substantial potential of palliative care services to reduce expenditures associated with hospitalisation while at the same time provide much needed and desired care in a setting that most patients express the wish for. Further work on the cost impact of new end of life care service models, developed through the Marie Curie Cancer Care Delivering Choice Programme, is encouraging as it shows a reduction in hospital admissions and increase in home deaths with stable overall costs. The scenarios we tested seem realistic; solid and robust given this and other work in the area of reduced acute utilisation. For example, NAO's own work in Sheffield (albeit just for 1 month) indicates 40% of admissions to acute care for end of life care might be unnecessary and Marie Curie's Delivering Choice work indicates reducing admissions is possible although the evidence on the length of stay is less clear. The model, however, is flexible and transparent. Thus, it can accommodate any future estimates that may be obtained from further research.

Our model starts to provide some important insights on the costs of the last year of life. One has to ask however, what could be done further. Clearly, the availability of good and solid cost data for non cancer conditions is crucial in getting a more accurate estimate of the potential economic consequences of end of life care expansion for those patients. Another direction would be the expansion of the model to other conditions such as dementia or renal failure. Similarly, availability of good quality cost data is fundamental; the cost of care for dementia patients in the community is expected to be radically different to cancer patients. Application to all of those conditions will result to better understanding of the potential of further expansion of palliative care services.

Another dimension relates to further refining the model by addressing some of its inherent limitations. Thus the Markov model can be made more dynamic and realistic. As was pointed out, the present Markov model is not fully dynamic (since deriving the transition probabilities assumes that the amount of time spent in a hospice by patients is not affected by the number of emergency admissions or the average length of stay). With more precise data, especially for the hospice provision we could possibly improve upon this limitation. Furthermore, this model assumes the transition probabilities to be fixed during the whole period of the last year of life which, as pointed out, is clearly not the case in real life. Thus, another improvement would be to obtain more accurate hospital data in order to overcome this limitation. It should be acknowledged, however, that this would allow for a more accurate prediction of place of death and how the costs are spread throughout the year, but would not impact on the overall cost figure or potential savings.

Hospitals are increasingly strained by providing care to chronically ill patients whose numbers continue to grow. At the same time it is vital to note that hospitals will continue to have an important role in delivering end of life care in the near, and perhaps, medium

future. The significance of planning, coordination and using resources efficiently cannot be overstated. The study by Gomes and Higginson (2008) and the projections they made underline the urgent need for planning structures and resources to accommodate a substantial increase of ageing and deaths for England (and Wales). Either inpatient facilities must increase substantially, or many more people will need community care towards the end of life from 2012 onwards. The next 5 years will be crucial for the development of incremental plans to expand structures of care in the right place, able to meet the increase in demand, the future needs of older people and ensure quality end of life care at home, in hospitals, nursing homes and hospices. However, many of the improvements envisioned can be achieved by better use of existing health and social care resources. It is likely, for example, that at least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay.

This study provides one of the two fundamental blocks for conducting a cost benefit analysis of palliative care expansion, as it estimates the potential benefits. It would be interesting and equally relevant to policy making to estimate what the costs would be for implementing those policies.

In conclusion, this study attempted in a systematic manner to utilise the best available data for England and estimate the financial implications and benefits of expanding palliative care services and allowing people to follow their wishes regarding place of death. It did so by linking potential reductions in emergency admissions and length of stay to the use of expanded end of life services utilising a flexible and transparent economic Markov model. Baroness Finlay of Llandaff at her speech at the House of Lords debate stressed that “The cost effectiveness of palliative care cannot be measured just in relation to the patient. There are opportunity-cost savings from futile interventions. Such costs are avoided by freeing up hospital beds by early discharge, by avoiding unnecessary hospital admissions through good anticipatory care and by decreasing morbidity in the bereaved by good care around death. There is a shift from high-tech to person-focused care. Based on current costs paid by the NHS, palliative care is the most cost-effective health service in the UK”.¹¹⁴ Our study provides a building block in documenting the potential economic benefits that may result as an effect of expanding end of life care to more patients.

This study contributes to the limited economic literature of end of life care. It shows the potential for releasing substantial amount of resources which in turn could be used to better meet patients’ wishes as they approach the end of their life. It further shows that there is room for improvement by providing those services to patients suffering from other conditions such as organ failure. Finally it reinforces the need for examining and expanding other alternative forms of care that are patient-centred.

¹¹⁴ House of Lords Debate; Palliative Care Bill, Friday, 23 February 2007.

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APPENDICES

Appendix A: Summary of studies

The table below summarises the studies that were reviewed with regards to identifying economic outcomes.

Table 17: Effects of palliative care during the last year of life, point estimates

	Country	Primary condition	Intervention	Hospital admissions	Hospital length of stay	ICU admissions	ICU length of stay	Other	Average cost savings per patient*
Addington-Hall et al. (1992) and Raftery et al. (1996), RCT	UK	Cancer	Two non-specialist coordinating nurses working across region		Shorter				–41% (£4774 vs. £8034)
Axelsson and Christensen (1998)	Sweden	Cancer	Hospital-based palliative support service; one specialist nurse, surgeon and other colleagues support	0%	–23% (3 vs. 10 days?)				–\$2,500 over last 3 months = –\$3220 in 2007\$
Brumley et al. (2003)	US	Multiple (COPD, CHF, cancer), no break down	Multidisciplinary home-based care	–74% hospital visits (2.4 vs. 9.4)					–45%, \$7,990 vs. \$14,570
Brumley et al. (2007)	US	Multiple (COPD, CHF, cancer), no break down	In-home palliative care plus usual care by interdisciplinary team providing symptom relief, patient and family education, and support services	–39%					–37%; –\$7,552 (2007\$)
Campbell et al. (2004)	US	Multiple Cancer Heart/other organ failure Dementia	US-style hospice care (incl. home care, hospital inpatient, skilled-nursing facility, outpatient facility)						+4% –12% +8%
Ciemins et al. (2007)	US	Multiple, no break down	Inpatient palliative care consultation service						+44% Mean daily cost –14.5%
Costantini et al. (2003)	Italy	Cancer	Palliative home care team		–37% (last 6 months) (–13%) 9.6 vs. 11 days				
Elsayem et al. (2004)	US	Cancer	Palliative care inpatient service at cancer center						Mean daily charges –38%
Enguidanos et al. (2005)	US	Multiple (CHF, COPD, cancer)	Home-based palliative care	ILIAD					Significant savings
Emanuel et al. (2002)	US	Cancer Heart COPD	US-type hospice care						–13 to –20% +19 to +30% –6 to –9%
Gade et al. (2008), last 6 months (RCT)	US	Multiple	Inpatient palliative care team	0%		–43%			–23%; –\$4,855
Gomez-Batiste, et al. (2006), last 6 weeks	Spain	Cancer	Palliative care services		19.2 vs. 25.5 days; –25%	40% lower rate of use			–61%
Grande et al. (2000),	UK	Multiple	Hospital at home service	.	.	.	.	–72% GP	.

(RCT), last 2 weeks							evening visits, –85% GP night visits	
Hughes et al. (1992), (RCT)	US	Cancer	Multi-professional 24h home care team operating from hospital		-			–\$769, (2007\$) – 1157
Hughes et al. (1997), last 6 months, meta-analysis	Multiple	Multiple	Home care		–2.5 to –6 days			–\$2650 to –\$6360 (2007\$: 3470 to 8326)
Hughes et al. (2000)	US	Multiple, incl. CHF, COPD, no breakdown	Team-managed home-based primary care					+12.1% (\$31,401 vs. 28,008)
Lewin et al. (2005), last 2 months	US	Ovarian Cancer	American style hospice	ILIAD				
Mor et al. (1990), (in Hearn and Higginson, 1998)	US	Unknown	US-type hospice care					–31% costs per day of care
National Hospice Organization (1995)	US	Cancer	US-type hospice care					–10.4%, \$36222 vs. \$32439 (2007\$)
O'Mahony et al. (2005)	US	Multiple, no break down	Inpatient consultation service					–\$2700 per palliative care consult
Penrod et al. (2006)	US	Multiple	Hospital-based palliative care consultation			–42%-points		–\$337 per day costs, no difference in pharmacy costs
Serra-Prat et al. (2001), last month	Spain	Cancer	Home palliative care		8.3 days vs. 12.2 days (–32%)			–71%; –€437
Smith et al. (2003)	US	Multiple	Specialist inpatient palliative care unit and team				–2.1 days (1.5 vs. 3.6 days)	–57% daily charges
Tamir et al. (2007)	Israel	Unknown	Home-specialised palliative care services vs. home non-specialised palliative care services					–30%
Taylor et al. (2007)	US	Multiple	US-type hospice care					–24% (\$7318 vs. \$9627 after initiation in hospice)
Tramarin et al. (1992)	Italy	AIDS	Home-care assistance	ILIAD				–35%

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Appendix B: Modelling methodology

B.1 Rationale and description of the model

Decision analytic modelling allows a rational, feasible, scientific and timely approach to measure the efficiency of new public policies in healthcare by using the best available evidence from different sources to produce detailed estimates of the economic consequences of different healthcare interventions.

RAND Europe, in collaboration with the National Audit Office (NAO), developed a decision model that represents the current situation in England with regard to the provision of healthcare services for patients with end of life conditions, in their last year of life, first for cancer then for organ failure (both heart and pulmonary diseases). The objectives were: a) to evaluate the end of life's total costs from the taxpayer's perspective and b) to obtain an idea of how much time patients spend in each care setting. Then, based on these results, we simulated different policy scenarios and examine the impact of different degrees of expanding the reach and availability of palliative care services.

Cancer

Of several mathematical models that could serve as adjuncts to the healthcare decision making process, the Markov model is distinguished by its simplicity, its ease of use in calculation, and its faithful representation of many healthcare problems.¹¹⁵ In this study we describe the design and implementation of a general Markov model, and illustrate its application in a healthcare decision analysis with complex features.

The problem considered here is the history of cancer patients in England who were finding themselves in an end of life (EOL) condition, which can be viewed for an individual patient as a sequence of particular states of healthcare. In particular, patients in the last year of their lives can receive care in different settings including acute care/hospital, hospice or home/community. By community we mean the care provided at the patient's home, which may also include some residential care such as visiting a nursing home. By hospice we mean inpatient treatment in hospices. Thus, a cancer patient's care may be classified into

¹¹⁵ See for example the paper by F. Sonnenberg and R. Beck (1993) "Markov Models in Medical Decision Making: A practical Guide", *Medical Decision Making* 13:322-338; also the book by A. Briggs, K. Claxton and M. Sculpher (2006) *Decision Modelling for Health Economic Evaluation*, Oxford University Press, Oxford.

one of three categories: acute care/hospital, hospice or home/community, which we shall hereafter call the *states* of the Markov model. Figure 12 illustrates this model.

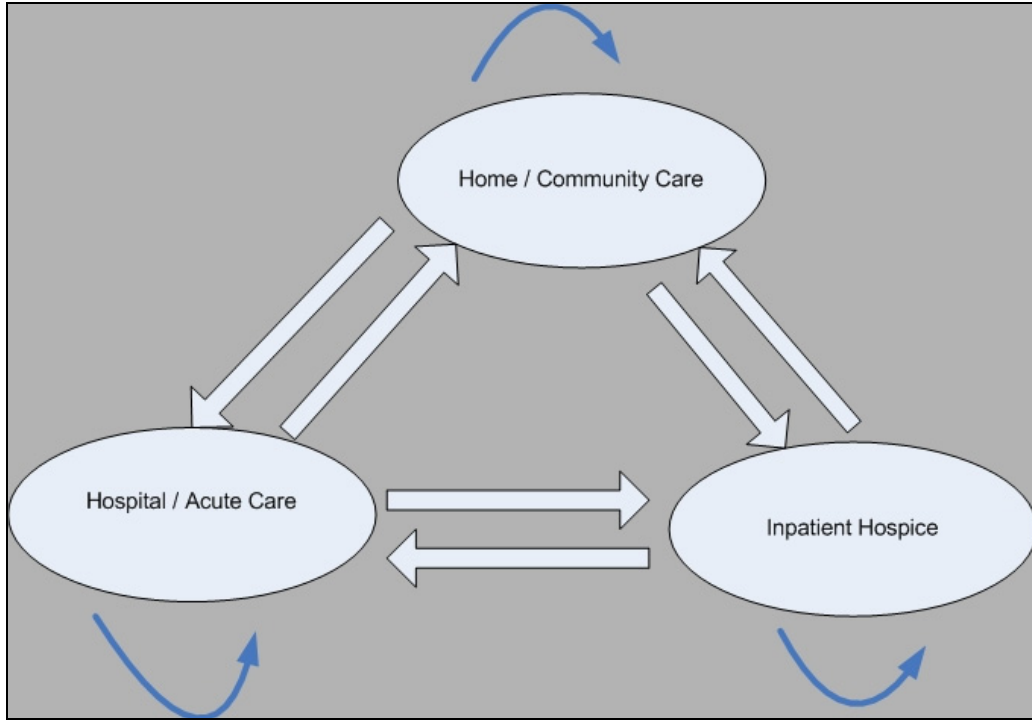


Figure 12: Transitions between the three states

Patients enter the model from the home/community care state. At any time t , the patient resides in just one of the states. In Figure 12 this is represented as a patient being in one of the three ovals. The possible changes of state, or *transitions*, which occur over the fixed time interval, from t to $t+1$, are illustrated in Figure 12 as arrows. At time $t+1$ the patient resides once again in one of three ovals: either by continuing at the current state or by moving to another state. Thus, it is possible to leave hospital, hospice or home via a transition (these states are termed as *non-absorbing* states).

In the Markov model the passage of time is represented by cycles, where t denotes the cycle count. Transitions among states occur instantaneously at each cycle. We define each cycle to be equal to one day. On the other hand, note that the model does not consider a death state (*absorbing* state) since we are interested in the states occurring during the patient's end of life (i.e. for $t = 1, 2, \dots, 365$ days) but before death. At day 366, all patients are assumed dead and exit the model.

Organ failure: Heart and Pulmonary Diseases

This is a similar model to the cancer case study. The general idea is identical, thus we shall not repeat the description. The only practical difficulty here resides in how to merge the data corresponding to the two diseases. This will be explained in detail when the model's parameters are discussed.

B.2 Data sources

This section summarises the data used in the economic modelling of the EOL care study. Sources included data from the Hospital Episode Statistics, the Office for National Statistics and from the Minimum Data Set. All data were supplied to RAND Europe by the NAO.

- Hospital Episode Statistics (HES) as stored by the Dr Foster Unit of Imperial College, London. The data used includes admissions over a 3-year period from 1 April 2003 to 31 March 2006.

The procedure for extracting the hospital admissions data was as follows; any patient with an EOL condition in any of the diagnosis fields was flagged. Records for patients who did not die in the period 1 April 2005 to 31 March 2006 or were aged less than 18 were removed. This produced a subset of admissions for adults who died in the 2005/06 financial year and had been diagnosed with an EOL condition at some point since 1 April 2003; these were categorised as “Cancer”, “Heartf” and “PulmD”. From this dataset, the mean length of stay (LOS) and number of inpatient non-elective (i.e. emergency) admissions within each of these categories were calculated.

This data was used to estimate the average number of emergency admissions for people who died of an EOL condition, i.e. for cancer we have:

$$\text{Average no. admissions} = \frac{\text{No. admissions for cancer patients who died (HES)}}{\text{Total no. cancer deaths (ONS)}}$$

- Office for National Statistics (ONS) “2006 Mortality Statistics for England” data. This reference volume presents statistics on deaths occurring annually in England and Wales. Statistics for deaths in previous years are included to show recent trends in mortality. The publication covers death counts and death rates tabulated by cause of death, and the age and sex of the deceased. Cause of death is coded according to the International Classification of Diseases (ICD). The total number of deaths for “Cancer”, “Heartf” and “PulmD” were extracted from this dataset. Also from the ONS 2006 calendar year we have used the total inpatient admissions to hospice for “Cancer”, “Heartf” and “PulmD”.
- The Minimum Data Set (MDS) was developed in 1995 by the National Council for Hospice and Specialist Palliative Care Services (now the National Council for Palliative Care, NCPC) in association with the Hospice Information Service at St. Christopher’s Hospice, London. In 1996 its use was recommended to the NHS by the Department of Health in Executive Letter 96(85). The Survey is of all hospice and specialist palliative care services located in England, Northern Ireland and Wales that are listed in the 2007 Directory of Hospice and Palliative Care Services published by Hospice Information. Not included in the survey are services for children, and specialist services such as those for HIV/AIDS or those provided by “site specific” cancer specialist nurses such as breast care nurses or chemotherapy nurses.

From the MDS we used the average length of stay in hospice, the proportion of hospice discharges to hospital, the proportion of hospice admissions from hospital and the proportion of hospice patients with cancer (the proportion for organ failure was assumed to be approximately the remainder).

All the data sources are summarised in Table 18:

Table 18: Data sources used for model development

Data Statistic	Source
Number of deaths	ONS 2006 Mortality Data
Emergency Admissions	2005/06 HES Data
[1] Cancer	= ICD10 codes C00-C097 Malignant Neoplasms (excluding deaths from non-malignancies)
[2] Heart Failure	= ICD10 Codes I50
[3] Pulmonary Disease	= ICD10 Codes J41.0 – J44.9 (inclusive) J961, D860, D862
Total inpatient admissions to hospice	ONS 2006 Data
Inpatient data	National Council for Palliative Care - MDS 2007 ¹¹⁶

¹¹⁶ “National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full Report for the year 2006-2007”, The National Council for Palliative Care, December 2007.

B.3 Assumptions for model development and analysis

Model assumptions

As discussed earlier, all patients entering the model are terminally ill (EOL conditions) over the course of their last year of life and progress through the model in daily cycles. We assume that all patients start in home/community care. At any stage patients can find themselves in any of the three states considered, i.e. hospital, hospice, home/community care, but they can be at one state only during a single cycle. For each of the 365 cycles patients have a probability 1 of being alive and they are assumed to die on cycle 366.

The main assumptions of the model described above are summarised in Table 19.

Table 19: Main model assumptions

Main assumptions underling the structure of the Markov model
• All patients are assumed with EOL conditions and in the last year of their life • The cycle length is equal to one day • Each patient is alive for 365 days with probability one and dies on day 366 • At each cycle (i.e. each day) a patient can be at one stage only • The transition probabilities depend only on the present state and not on the past states • The transition probabilities are supposed to be fixed for all cycles

Model development

We assign a certain and fixed probability value for each transition between states, which we define in more detail below. That means, the transition probabilities on a given day are determined by the state which the patient is in on that day; they do not depend on the previous states. This is a simplification embedded in the Markov model, and as such, does not necessarily correspond to real life situation. However, it is simple to understand and implement and is likely to be relatively robust, given that we focus on the population's average costs.

If we define the transition states as:

1= hospital/acute care,

2 =hospice and

3 =home/community care,

then the Markov model is fully defined by the set of the transition probabilities p_{ij} which can be collected in a 3×3 matrix, called the transition probability matrix of the model.

p_{11}	p_{12}	p_{13}
p_{21}	p_{22}	p_{23}
p_{31}	p_{32}	p_{33}

Transition probabilities and their properties are shown and explained in detail in Table 20.

Table 20: Model probabilities for end of life care

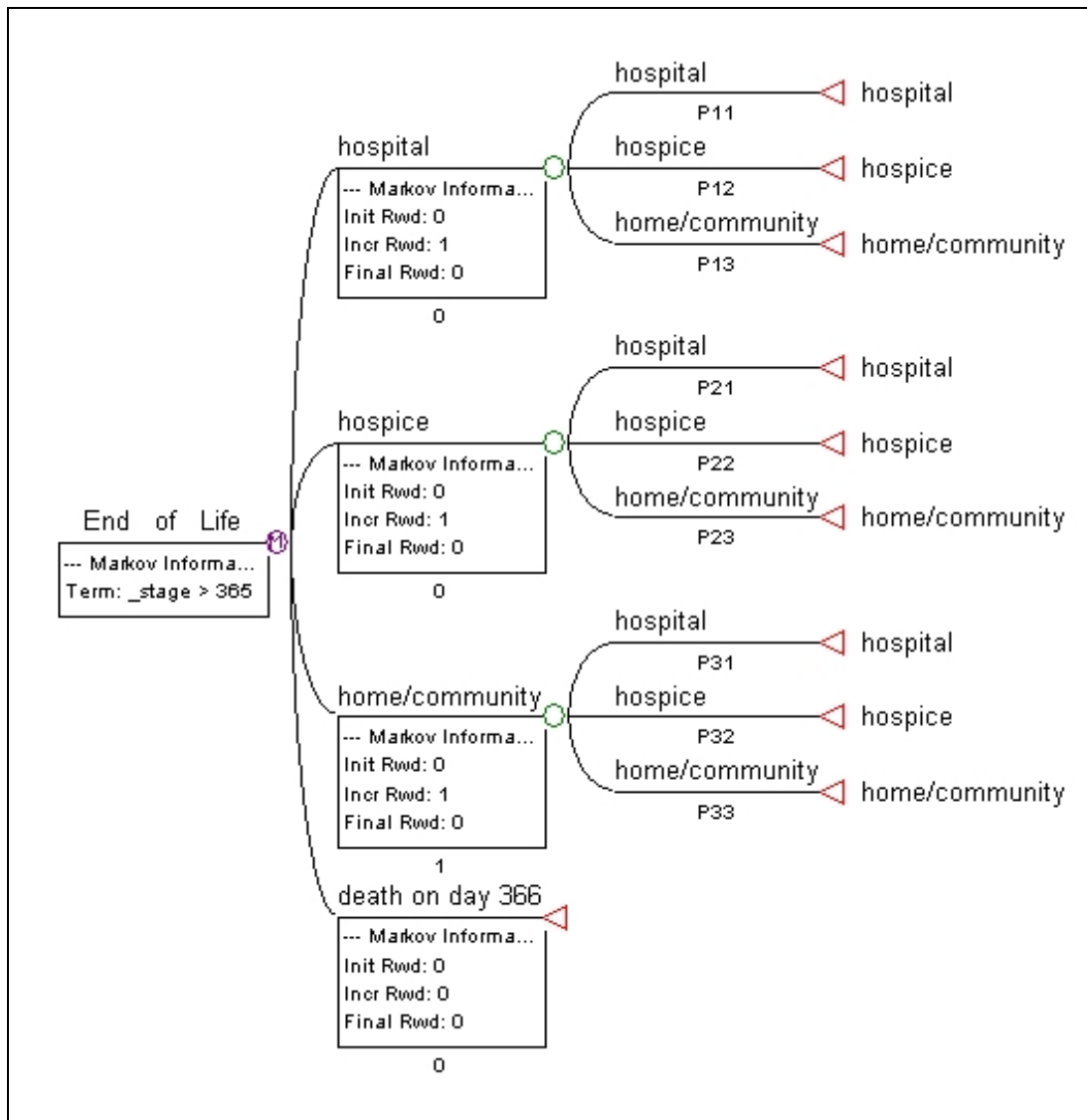
Symbol	Notes on transition probabilities p_{ij} (note that $0 \leq p_{ij} \leq 1$)
p_{11}	Probability of receiving hospital care after spending the last day at hospital
p_{12}	Probability of discharge to hospice after spending the last day at hospital
p_{13}	Probability of discharge to home/community care after spending the last day at hospital
p_{21}	Probability of hospital care after receiving care at hospice
p_{22}	Probability of hospice care after spending the last day at hospice
p_{23}	Probability of discharge to home/community care after spending the last day at hospice
p_{31}	Probability of hospital care after receiving care at home/community
p_{32}	Probability of discharge to hospice after spending the last day at community care
p_{33}	Probability of community care after spending the last day at community care
$\sum_{j=1}^3 p_{i,j} = 1$ for $i = 1, 2, 3$	the sum of each row of the transition probability matrix of the Markov model sums to unity; this is a natural consequence of the fact that all three mutually exclusive events span the event space.

The calculation of the transition probabilities is based on a number of assumptions and discussed later in the report. We have to note here that the transition probabilities are a very important intermediate product for the purpose of this exercise (i.e. the calculation of the total healthcare costs and the number of days spent in each state of care) coming from the model parameters (raw data) which we shall discuss now.

Model estimation

Once the transition probabilities are calculated, to estimate the end of life care costs and days spent in each care setting for cancer (and organ failure) patients, we use *TreeAge Pro Suite 2008* software to run the Markov state-transition model. It is a powerful software tool for modelling situations where there is a need for flexible transitions among different states during a specified period of time.

The model with the transition probabilities can be depicted within the TreeAge software as illustrated in Figure 13.



NOTE: M = Markov node

Figure 13: Overview of the Markov model for end of life patients within the *TreeAge Pro* software specification

It is seen that the death state is also included here for completeness, although it will not interfere at all with the model's calculations. Also note that below the box of "home/community" state there is a figure equal to unity (as opposed to the 0s below the other boxes), which implies that patients enter the model from this particular state with probability 1, as discussed earlier.

Model parameters: cancer

The parameters used in the model for cancer and their sources, are shown in Table 21.

Table 21: Parameters for Markov model (cancer)

Source	Figure	Description
MDS (2007)	12.9	Average length of stay in hospice
MDS (2007)	0.056	Proportion of hospice discharges to hospital
MDS (2007)	0.282	Proportion of hospice admissions from hospital
ONS (2006)	43050	Inpatient admissions to hospice
MDS (2007)	0.927	Proportion of hospice patients with cancer
HES 2005/06	126779	Deaths from cancer (excluding deaths from non-malignancies)
HES 2005/06	10.98	Mean length of stay for hospital admissions
HES 2005/06 ¹¹⁷	1.62	Admissions to hospital per patient
HES 2005/06 ¹¹⁸	1.12	Emergency hospital admissions per patient
Expert opinion	0.90	Proportion of hospice admissions in last year of life

NOTES: Figures based on MDS for England where based on the fact that the vast majority of the respondents were from England.

Model parameters: organ failure

In order to run the two diseases lumped (i.e. as an organ failure case) we opted for a linear combination of proportional weights solution. This procedure needs to be followed for the mean LOS and for the Emergency and Total admissions to hospital. For instance, the LOS, emergency and total number of hospital admissions. We propose to use the hospital emergency and elective admissions data as follows to get the proportions:

$$\text{LOS(organ failure)} = q * \text{LOS(heart)} + (1-q) * \text{LOS(pulm)},$$

where q is the proportional weight corresponding to heart disease with respect to the total.

The sum of the organ caused deaths (ONS data) is calculated first, given that we have Heart Failure (total deaths)=7655 and Pulmonary Disease (total deaths)=21785; thus, summing up, we derive 29440 deaths for organ failure which gives the following proportions:

$$7655/29440 = 0.26, \text{ for Heart failure; } 21785/29440 = 0.74, \text{ for Pulmonary failure.}$$

For the joint LOS of organ failure:

¹¹⁷ Due to the fact that some patients did not have an inpatient hospital stay in their last year of life, for the 'average' patient in our model the number of admissions and the number of emergency admissions was adjusted to take account of the fact that not all patients have an inpatient stay.

¹¹⁸ Idem.

$$\begin{aligned}\text{LOS}(\text{organ failure}) &= 0.26 * \text{LOS}(\text{heart}) + 0.74 * \text{LOS}(\text{pulm}) = \\ &= 0.26 * 16.84 + 0.74 * 12.39 = 13.547,\end{aligned}$$

since from HES data we knew that $\text{LOS}(\text{heart})=16.84$ and $\text{LOS}(\text{pulm})=12.39$.

With similar calculations we derived the figures 3.062 and 2.929 corresponding to hospital total and emergency admissions respectively

If we assume 171 organ failure patients (ONS hospice data indicate 143 deaths for Pulmonary failure and 28 for Heart failure, thus $143+28=171$) had an average of 1.2 admissions each as a hospice patient (from MDS: total stays ended/total number of patients=1.2), this implies $1.2 * 171 = 205$ admissions and the corresponding proportion of the total in-patient admissions would be: $205/43050 = 0.0047665$. The parameters used in the model for organ failure and the sources they were taken from, are shown in Table 22.

Table 22: Parameters for Markov model (organ failure)

Source	Figure	Description
MDS (2007)	12.9	Average length of stay in hospice
MDS (2007)	0.056	Proportion of hospice discharges to hospital
MDS (2007)	0.282	Proportion of hospice admissions from hospital
NAO calc and ONS (2006)	43050	Inpatient admissions to hospice
MDS (2007)	0.0047	Proportion of hospice patients with organ failure
HES 2005/06	29440	Deaths from organ failure
HES 2005/06	13.547	Mean length of stay for hospital admissions (based on the LCOF calculation)
HES 2005/06	3.062	Admissions to hospital per patient (LCOF)
HES 2005/06	2.929	Emergency admissions per patient (LCOF)
Expert Opinion	0.90	Proportion of hospice admissions in last year of life

NOTES: LCOF = Linear Combination of Organ failure using proportional weights for heart and pulmonary diseases based on the HES data.

In the absence of better hospice data, we used the whole sample's characteristics (of 43050 patients) for: the average hospice LOS (i.e. 12.9 days), the proportion of hospice discharges to hospital (0.056) and the proportion of hospice admissions from hospital (0.282). For the same reason we also used the number of organ failure patients who die in hospice as a proxy for the proportion of organ failure patients who had an inpatient admission to hospice in the last year of life (there may be some patients with organ failure who are admitted to a hospice, stabilised and discharged to die elsewhere but this number is likely to be very small).

B.4 Estimation of the transition probabilities

Transition probabilities for cancer end of life model

The transition probabilities between the three states considered in the Markov model (recall that 1=hospital, 2=hospice and 3=home/community care) can be gathered in a 3×3 matrix and are found to be as follows:

$p_{11} = 0.90893$	$p_{12} = 0.00449$	$p_{13} = 0.08658$
$p_{21} = 0.00434$	$p_{22} = 0.92248$	$p_{23} = 0.07318$
$p_{31} = 0.00467$	$p_{32} = 0.00059$	$p_{33} = 0.99474$

The way that the above matrix is derived is further discussed in the following section. The data sources used for the derivation were the HES¹¹⁹ data sent to RAND Europe by the NAO and survey data in the MDS Report¹²⁰ of the NCPC.

B.5 Derivation of the transition probabilities

Fundamental assumption

The problem discussed in this section is determining from the data available the transition probabilities between three states for cancer patients¹²¹ in the last year of their life. The basic assumption is that the process is Markovian, i.e. that the transition probabilities are stable over the year and are not affected by a specific patient's history. This assumption might not be justified in detail (i.e. as a faithful representation of individual experience) but is reasonable as a working hypothesis at the cohort or average patient level.

A particular concern here is that the probability of discharge appears from the data to be a function of the length of stay, for both hospital and hospice. Because the intention is to use the formulae at aggregate level, we do not believe it is possible to exploit the full information available concerning the distribution of length of stay. Instead we work with average discharge rates.

A second issue is that the different transition probabilities may well vary over the year under consideration even for the aggregate of patients. Here we have some possibilities of extending the model. The basic concepts of the transition matrix apply for any well-defined group of patients: we could calculate functions $Q_i(x)$ and $p_{ij}(x)$ with x , for example, referring to patients 0–3, 3–6, 6–9 and 9–12 months from death, or any other convenient classification for which we have data.

However, even if we were to decide to undertake calculations for shorter time periods than a year, it seems useful to start with the annual averages.

¹¹⁹ Hospital Episode Statistics (HES) is the national statistical data warehouse for England of the care provided by NHS hospitals and for NHS hospital patients treated elsewhere. HES is the data source for a wide range of healthcare analysis for the NHS, Government and many other organisations and individuals.

¹²⁰ “National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full Report for the year 2006-2007”, The National Council for Palliative Care, December 2007.

¹²¹ It seems that for patients with other illnesses a simpler model might suffice as hospice care is very largely used by cancer patients (92.7% see row 11 of the Table below).

The working model

Let Q_i be the average proportion of these patients in each state on any day and let p_{ij} be the probability that a patient in state i makes the transition to state j on any day. This gives us a system of equations with 12 unknowns: 3 Q values and 9 p values.

Obviously, by definition:

$$Q_1 + Q_2 + Q_3 = 1$$

Also, because of the properties of probabilities:

$$p_{11} + p_{12} + p_{13} = 1$$

$$p_{21} + p_{22} + p_{23} = 1 \text{ and}$$

$$p_{31} + p_{32} + p_{33} = 1$$

The average number of patients in state 1 on one day can be determined by the numbers in each state on the previous day. Transition probabilities, the number in state 1, can be obtained by:

$$Q_1 p_{11} + Q_2 p_{21} + Q_3 p_{31}.$$

But because Q_1 is the average over the year, this number must be equal to Q_1 . Similar arguments can be applied for states 2 and 3, leading to:

$$Q_1 = Q_1 p_{11} + Q_2 p_{21} + Q_3 p_{31}$$

$$Q_2 = Q_1 p_{12} + Q_2 p_{22} + Q_3 p_{32} \text{ and}$$

$$Q_3 = Q_1 p_{13} + Q_2 p_{23} + Q_3 p_{33}$$

However, these three equations are not independent, because the third can be shown to be linearly dependent on the second. We therefore have six independent equations following from the structure of the system (one on Q , three on p and two on the combination of p and Q).

Thus we can reduce the number of unknowns in the system from 12 to 6. We therefore need six independent pieces of information to be able to determine all the numbers.

Table 23: Data for deriving the transition probabilities

	Statistic	Value	Source	Comments
1	Average number of Length of Stay (LoS) days in hospital per cancer patient	10.98	NAO calculations from HES data 2004/5	Assumed equal for emergency and elective admissions
2	Mean length of stay per hospice admission	12.9 days	MDS (England, Wales and Northern Ireland) 2006/7	
3	Mean number of total admissions in last year of life per cancer patient	1.62	HES and NAO calculations, memo of 18 July 2008	Excludes non-malignancies
4	Mean number of emergency admissions in last year of life per death	1.12	HES and NAO calculations, memo of 18 July 2008	Excludes non-malignancies
5	Proportion of hospice admissions in last year of life	0.90	An assumption has been made that 90% of hospice admissions of cancer patients are in the last year of their life	There is no quantitative basis for this value, but it seems reasonable and the results are not very sensitive to it
6	Proportion of discharges from hospice to hospital	5.6% (0.056)	MDS 2006/7	
7	Proportion of patients in a hospital prior to an admission to a hospice	28.2% (0.282)	MDS 2006/7	
8	Number of patients who has an inpatient admission to a hospice in 2006/07	43,050	NAO calculations, memo of 11 July 2008	
9	Proportion of hospice inpatients with a primary diagnosis of cancer	92.7% (0.927)	MDS 2006/7	
10	Deaths from cancer in 2005/6	126,779	ONS 2004/5	Excludes non-malignancies

Calculations

On the basis of the data of Table 23, a number of calculations can be made.

Average totals per category

Q1: Number of days a cancer patient will spend in hospital care in the last year of life is $(\text{Mean Admission} * \text{LoS}) = 1.62 * 10.98 = 17.7876$, then, following the previous calculation, we have: $17.7876 / 365 = 0.048733$.

Q₂: from rows 2, 8, 9 and 10 of Table 23, we derive: $12.9 * 43050 * 0.927 * 0.9 / (126779 * 365) = 0.010013$.

Q₃: $= 1 - Q_1 - Q_2 = 0.941254$.

Transitions from hospice

p_{22} : If the mean length of stay in hospice is 12.9 days (Table 23, row 2), the probability of discharge per day is $1/12.9 = 0.0775^{122}$, so we get $p_{22} = \mathbf{0.92248}$. This calculation may be a good approximation (it might be not precise if the length of stay given in Table 23 is for all patients, whereas what we need here is for cancer patients discharged alive but in the last year of their lives).

p_{21} : $= 0.0775 * 0.056$ (Table 23, row 6) = **0.00434**.

p_{23} : $= 1 - p_{21} - p_{22} = \mathbf{0.07318}$.

Remaining in hospital and entering hospital from home

p_{11} : Data from row 1 of Table 23 gives the average length of stay in hospital as 10.98 days and thus $p_{11} = 1 - 1/10.98 = \mathbf{0.90893}$ (a similar calculation to p_{22} and subject to several of the same reservations).

p_{31} : Data from row 3 of Table 23 gives the rate of admissions to hospital as 1.62 per death for cancer patients in the last year of life. These must come from home or hospice, implying:

$Q_2 p_{21} + Q_3 p_{31} = 1.62 / 365$, that is:

$$p_{31} = (1.62/365 - Q_2 p_{21}) / Q_3 =$$

$$= ((1.62/365) - 0.010013 * 0.00434) / 0.941254 = \mathbf{0.00467}$$

Transitions to hospice

The rate of admissions to hospice can be approximated. We have 43,050 admissions to hospice, of which 92.7% are cancer patients (rows 8 and 9 of Table 23). Using (Table 23, row 5) that 90% of these are in the last year of life we get:

$(43050 * 0.927 * 0.90) / (126779 * 365) = 0.000776167 = RH$, the rate of hospice admissions per day per death. These patients can come from home or hospital, so we get

$$Q_1 p_{12} + Q_3 p_{32} = RH$$

Moreover, we know the ratio of origins of admissions to hospice (row 8 of Table 23)

$$p_{12} / p_{32} = HH = (0.282 * Q_3) / ((1 - 0.282) * Q_1) = 7.5859$$

Therefore we obtain:

$$p_{32} = RH / (HH Q_1 + Q_3) = \mathbf{0.00059}$$

¹²²We assume a uniform discharge rate, i.e. an exponential distribution of lengths of stay, which implies that the mean (12.9 days) is the inverse of the discharge rate. This is not exactly correct, as discussed above.

and

$$p_{12} = HH \ p_{32} = \mathbf{0.00449}$$

Going home

$$p_{13} = 1 - p_{11} - p_{12} = \mathbf{0.08849}$$

$$p_{33} = 1 - p_{31} - p_{32} = \mathbf{0.99499}$$

Hence we can state the complete matrix of probabilities as follows:

Q ₁	p ₁₁	p ₁₂	p ₁₃	0.048733	0.90893	0.00449	0.08658
Q ₂	p ₂₁	p ₂₂	p ₂₃	0.010013	0.00434	0.92248	0.07318
Q ₃	p ₃₁	p ₃₂	p ₃₃	0.941254	0.00467	0.00059	0.99474

An MS Excel spreadsheet has been prepared to illustrate the calculation and facilitate changes.

Transition probabilities for organ failure (heart and pulmonary disease)

The data sources and the methods followed are similar for the cancer case with the addition of merging the two types of diseases data as explained in section B.3. In particular, we have used the MS Excel spreadsheet with the following inputs:

Average LOS in hospice = 12.9; Proportion of hospice discharges to hospital = 0.056;

Proportion of hospice admissions from hospital = 0.282;

Inpatient admissions to hospice = 43050, of which the proportion of hospice patients with Organ Failure = 0.0047; Deaths from Organ Failure = 29440;

LOS stay for hospital admissions = 13.547;

Admissions to hospital per patient = 3.062; Emergency admissions per patient = 2.929;

Proportion of hospice admissions in last year of life (educated guess) = 0.90.

Thus, for organ failure the transition probabilities between the three states are found to be:

p ₁₁ = 0.92618	p ₁₂ = 0.00004	p ₁₃ = 0.07377
p ₂₁ = 0.00434	p ₂₂ = 0.92248	p ₂₃ = 0.07318
p ₃₁ = 0.00947	p ₃₂ = 0.00001	p ₃₃ = 0.99052

B.6 Estimation of the costs

The average daily patient costs for Hospital, Hospice and Home, are given in Table 24. All prices are taken from the paper by Coyle et al¹²³ (1999) and are adjusted for inflation. The paper offers a comprehensive analysis of the cost of palliative care in the UK and is a basic reference as it offers clear comparisons between hospital, hospice and home care costs.

123 D. Coyle et al., "Costs of Palliative Care in the Community, in Hospitals and in Hospices in the UK," *Critical Reviews in Oncology/Hematology* 32 (1999): 71.

Table 24: Daily patient costs

	Hospital	Hospice	Home
1994 daily prices as in the original paper (Coyle et al. 1999)	155.955	211.96	15.89
2007 daily prices inflation adjusted (ONS: CPI index-Health)	222.016	301.744	22.621

Note: See Appendix C for the inflation-adjustment of prices using the ONS CPI index-Health.

Currently if the figure from Coyle et al (1999) paper is adjusted by the ONS health index (see Appendix C) then the cost of a day of hospice inpatient care is £301.774. This figure should be adjusted to take account of the proportion of costs met by the state for NHS and voluntary hospices and the relative number of patients admitted to them. The hospice cost from the taxpayer's perspective is adjusted to £132.479 (see Appendix E for the precise calculation). The home/community care costs were also revised accordingly based on deaths from cancer in the community occurring in the home, deaths from cancer in the community occurring in some form of residential care and by taking into account figures from Curtis (2007)¹²⁴. It was calculated that the home/community care cost per day should be corrected to £28.02 (see Appendix D for the calculation); summarising we have daily patients costs as shown in Table 25.

Table 25: Daily patient costs after adjustments (see Appendices D and E for details)

NAO calc	£28.02	Home/community care cost per day
Coyle et al	£222.016	Hospital cost/day
NAO calc	£132.479	Hospice cost/day

For hospital admissions, we are also interested in estimating the cost of emergency admissions as opposed to elective ones. From a report drawn up by Curtis (2007), we calculate that the average cost per patient journey with emergency ambulance is £257. This gives us an indication of some of the additional costs associated with emergency hospital admission.

B.7 Sensitivity analysis

When data are collected and assumptions are made within an economic evaluation framework, some uncertainty arises naturally. The impact of this uncertainty is assessed by undertaking a sensitivity analysis. In this report we shall use univariate (one-way) sensitivity analysis, which is an exploration of the impact on the results of changing the value of one parameter while keeping the values of all other parameters unchanged (*ceteris paribus*).

¹²⁴ Lesley Curtis, *Unit Costs of Health and Social Care 2007*, (University of Kent, 2007), Table on page 100.

One-way sensitivity analyses were conducted using variables in the model with results assessed via comparative tables and a tornado diagram. We examined the effect of changing several different model parameters, including:

- for hospice: the patients' mean length of stay, the total inpatient admissions to hospice, the proportion of hospice patients per case (cancer/organ failure) and the proportion of hospice admissions in last year of life;
- for hospital: emergency hospital admissions per patient and the elective hospital admissions per patient;
- furthermore, one-way sensitivity analyses were conducted for the healthcare costs per day, that is, the costs for home/community care, hospital and hospice.

In coordination with the NAO we have identified the range of alternative values that we then substitute into the baseline case.

All the parameters under sensitivity analysis are summarised in the following Table 26.

Table 26: Summary of parameters under sensitivity analysis

Block of variables	Base figure		Description
	Cancer	Organ failure	
Hospice	12.9	12.9	Average length of stay in hospice: base $\pm$ 1.0
	43,050	43,050	Total inpatient admissions to hospice: base $\pm$ 5% and 10%
	0.927	0.0047	Proportion of hospice patients per case: base $\pm$ 5% and +100%
	0.90	0.90	Proportion of hospice admissions in last year of life, with range: [0.70–1.0]
Hospital	1.62	3.062	Admissions to hospital per patient (Elective $\pm$ 10%)
	1.12	2.929	Emergency hospital admissions per patient $\pm$ 10%
Costs	£28.02	£28.02	Home/Community Care cost per day: £28.02 $\pm$ 10% and 20%
	£222.016	£222.016	Hospital cost per day: £222.016 $\pm$ 10% and 20%
	£132.479	£132.479	Hospice cost per day: £132.479 $\pm$ 10% and 20%

B.8 Limitations

Limitations of the model:

The model implicitly makes stationarity assumption. The transition probabilities are considered fixed during the whole period of the last year of life, which is clearly not the case in real life. For instance, a patient has higher probability of a hospital admission during the last days of his life as opposed to an earlier period of the last year of life.

The model is not fully dynamic. During the analysis we have identified that the transition probabilities related to hospice care were remaining stable although the hospital's LOS and the days of acute care were varied substantially.

It is also important to note that the Markov model reaches a steady-state relatively fast. This is because of:

- a. The specification of the structure of the transition probability matrix – this refers to the very high values in its diagonal relative to the non-diagonal elements.
- b. The choice of the daily-cycle for the end of life model.

Limitations with respect to the data:

Overall comment:

The HES data is based on the 2005/06 financial year, whilst the ONS data is for the calendar year 2006. This is because we only have ONS data for 2006 in sufficient detail to obtain the number of deaths for specific conditions such as heart failure. Because the data sets overlap by 3 months, but do not cover the exact same period this is acknowledged as a small limitation, although number of deaths by condition do not vary significantly over such a short period of time. Since there is some uncertainty around the exact numbers we have varied them in the sensitivity analysis of the base case.

Particular comment for the HES data:

- 1) Cause of death different to EOL condition. The cause of death is not recorded in the data set and so people who had been diagnosed with an EOL condition may have died from a different condition. For example, a cancer patient who had an emergency admission for any reason in the last year of life would be captured by HES (and hence would feature in the numerator of the calculation of number of emergency admission per person). However, if they did not die of cancer, but of another cause they would not be captured by the ONS mortality statistic (and hence would not feature in the denominator of the calculation; see also equation in section A.2). This would cause a small overestimate in the average number of admissions for all people dying of an EOL condition.
- 2) However, our extraction of the HES data excludes patients with more than one of the conditions of interest, for example a patient with cancer and dementia, regardless of what is recorded as the cause of death. This means that, for example, some people who had cancer recorded as their cause of death will not have their admissions captured as they had a dual diagnosis (i.e. they feature in the denominator of the calculation of average number of admissions, but not the numerator). This will lead to an underestimate of the number of admissions in the last year of life.
- 3) It is believed that given these limitations the number of admissions is likely to be an underestimate meaning the model will produce conservative minimum estimates of the level of potential savings.
- 4) Not all admissions may be related to the EOL condition. Since the recording of the diagnosis code may not always be systematic (i.e. the EOL condition may be recorded on the first but not the subsequent admission) we included all admissions for anyone who had an EOL diagnosis at any time.

- 5) Incorrect coding in the dataset. Any errors in coding will effect the Hospital Episode Statistics data set, however, given it is the basis for hospital's remuneration, it is thought to be adequately correct and consistent.
- 6) Linking of the death data field. It is possible that the linking of the admissions data to the data signifying the patients' date of death may not be entirely accurate; however, our expert advisers believed that the linking was appropriately accurate.

Limitations with respect to the costs:

We have used the same costs per day for both cancer and organ failure cases. This might be of importance especially for the home/community care costs which seemingly affect the final total cost for the whole cohort more than any other model parameter.

Appendix C: Inflation-adjusted costs

Calculation of the inflation-adjustment of prices using the Office of National Statistics (ONS) CPI index-Health:

From the Office of National Statistics (ONS) web-site we have the following CPI index-Health related¹²⁵.

Year	Index
1988	52.7
1989	57
1990	61.9
1991	68.1
1992	72.7
1993	73.6
1994	74.6
1995	75.3
1996	76.9
1997	79
1998	81.8
1999	83.4
2000	85.8
2001	89
2002	92.4
2003	95.5
2004	97.2
2005	100
2006	102.8
2007	106.2

From the Office of National Statistics (ONS) web-site we have the following CPI index-Health related¹²⁶.

The inflation adjustment is achieved as follows: $\text{Price}_{2007} = \text{Price}_{1994} * (106.2/74.6)$.

¹²⁵ From <http://www.statistics.gov.uk/statbase/TSDSeries1.asp> we have chosen and downloaded the data coded as: mm23; 1.1: D7BZ: CPI INDEX 06: HEALTH- estimated pre-97 2005=100

¹²⁶ From <http://www.statistics.gov.uk/statbase/TSDSeries1.asp> we have chosen and downloaded the data coded as: mm23; 1.1: D7BZ: CPI INDEX 06: HEALTH- estimated pre-97 2005=100

Appendix D: Analysis of community care costs

Given the fact that the costs from the Curtis (2007) report are for supporting elderly people in their own homes, these cannot be used as a proxy for the cost of supporting cancer patients. As a result, some consideration needs to be given to the cost of people living in residential care.

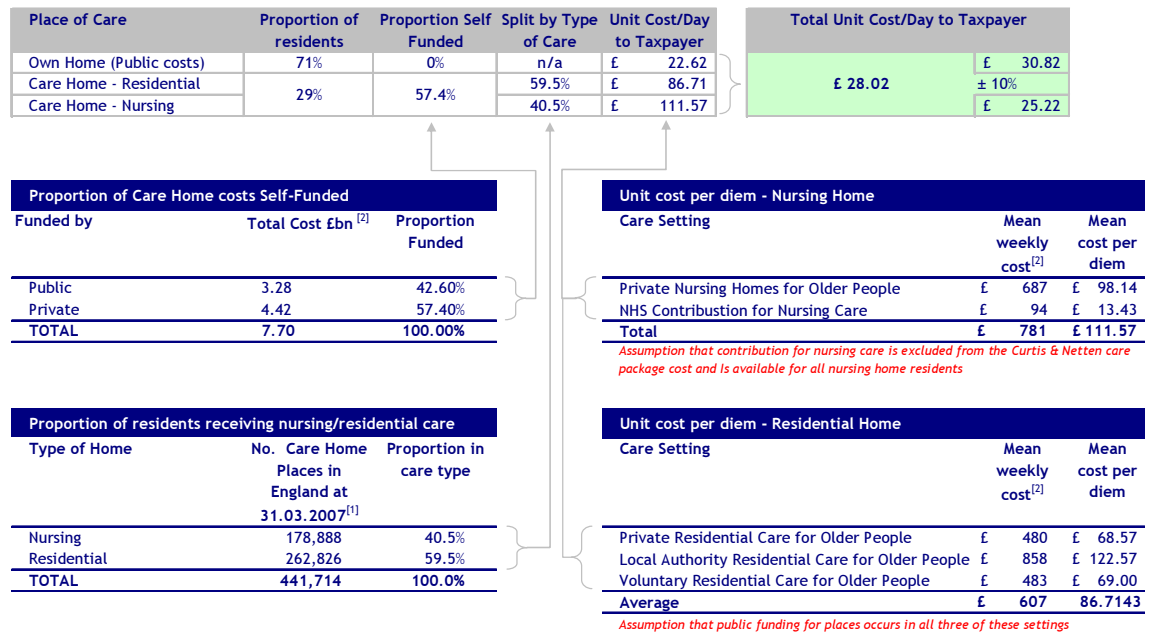
Accordingly the NAO has developed a cost per diem measure for community care based on 71% of deaths from cancer in the community occurring in the home; and 29% of deaths from cancer in the community occurring in some form of residential care¹²⁷.

Data from Curtis (2007) is used for the cost of residential care and this is combined with data from the Commission for Social Care Inspection on number of places and proportion of costs met by individuals and the data to develop a cost. This is then combined with the index-adjusted figure for community care from the Coyle et al (1999) paper.

Figure 14 sets out the method of calculation and the sources used. Consequently, the value calculated for a day of community care is **£28.02**.

¹²⁷ Based on 2006 mortality statistics shared with Rand Europe.

Care in the Community



References

[1] Unit Costs of Health & Social Care 2007, Curtis & Netten

[2] The State of Social Care in England 2006-07, CSCI

Figure 14: Care in the community (Source: RAND Europe and NAO)

Appendix E: Hospice costs and patient numbers

On examining inpatient Minimum Data Set (MDS) figures 2006/07 it has become apparent that only around 88% of inpatient units in England responded and these were a mixture of NHS- and voluntary-run hospices (83% of all NHS hospices responded and 91% of all voluntary hospices responded).

This has certain implications for the costs of hospice care and the number of patients receiving an inpatient admission. The key facts are displayed in Table 27:

Table 27: Key facts for hospices

	Voluntary	NHS
Patients admitted in	29,817 (MDS)	8,046 (MDS)
Proportion of all patients	78.75% (MDS)	21.25% (MDS)
Units Responding	112	34
Proportion of funding provided by the state	32% (NAO survey and Help the Hospices)	88% (NAO Survey)

Number of hospice patients

If 146 responses represent 88% of the population then the total number of units is 166.

Clearly the number of patients who have an inpatient admission currently being used (37,863) is an underestimate and is subject to some uncertainty.

It is proposed that for the baseline example non respondents are assumed to have had the same number of mean admissions as non respondents (37,863/146), therefore:

Number of patients receiving an admission (base) = $(37,863/146) \times 166 = \mathbf{43,050}$

This is varied by 10% in carrying out sensitivity analysis of the base case.

Number of patients receiving an admission (max) =

$$= 37,863 + 20 \times ((37,863/146) + (37,863/146) \times 0.1) = 43,568$$

Number of patients receiving and admission (min) =

$$= 37,863 + 20 \times ((37,863/146) - (37,863/146) \times 0.1) = 42,531$$

Hospice costs

Currently if the figure from Coyle et al. (1999) is adjusted by the ONS health index then the cost of a day of hospice inpatient care is £301.774.

This figure should be adjusted to take account of the fact that the state only meets 32% of voluntary hospice costs. However, this is an under estimate since a significant proportion of patients have an admission to an NHS-run hospice which have a far higher proportion of their costs provided by the state.

Thus, we assumed that the proportion of patients each type of hospice takes is the same for respondents and non respondents and the cost of a day of hospice care is calculated as:

$$301.774 * ((0.2125 * 0.88) + (0.7875 * 0.32)) = \textbf{£132.479}$$

Appendix F: Caregivers burden selected literature

This section contains a selection of references and abstracts of the literature that examines the carers' burden of patients suffering from terminal illnesses.

1. Title: Burden to others and the terminally ill

Reference: Chochinov HM, Kristjanson LJ, Hack TF, Hassard T, McClement S, Harlos M.

Journal of Pain and Symptom Management. 2007 Nov; 34(5): 463-71.

ABSTRACT

Studies of patients who are terminally ill consistently identify strong associations between "sense of burden to others" and marked end-of-life distress. However, little research has addressed the issue of burden to others among patients nearing death. The aim of this study was to carefully examine "burden to others" and clarify its relationship with various psychosocial, physical, and existential issues arising in patients who are terminally ill. A cohort of 211 patients with end-stage cancer was assessed, using an assortment of validated psychometrics to document psychosocial, physical, and existential aspects of their end-of-life experience. This included an assessment of their sense of "burden to others." Forty percent of participants indicated a negligible sense of burden to others, scoring within the lowest quarter on an ordinal measure of "burden to others;" 25% scored within the second lowest quarter; 12% within the third quarter; and 23% within the highest or most severe range. The most highly correlated variables with "sense of burden to others" included depression ($r=0.460$; $df=201$, $P<0.0001$), hopelessness ($r=0.420$; $df=199$, $P<0.0001$), and outlook ($r=0.362$; $df=200$, $P<0.0001$). Four variables emerged in a multiple regression analysis predicting burden to others, including hopelessness, current quality of life, depression, and level of fatigue [$R^2_{adj}=0.32$, $F(6,174)=13.76$, $P<0.0001$]. There was no association between sense of burden to others and actual degree of physical dependency. Feeling a sense of burden to others is common among dying patients. Although 40% of the sample reported little in the way of sense of burden to others, the remainder endorsed higher degrees of burden-related distress, with 23% scoring within the most severe range. The lack of association between "sense of burden to others" and the degree of physical dependency suggests this perception is largely mediated through psychological and

existential considerations. Strategies that target meaning and purpose, depression, and level of fatigue could lessen this source of distress and enhance quality, dignity-conserving care.

2. Title: Dying of cancer in Italy: impact on family and caregiver. The Italian Survey of Dying of Cancer.

Reference: Giorgi Rossi P, Beccaro M, Miccinesi G, Borgia P, Costantini M, Chini F, Baiocchi D, De Giacomi G, Grimaldi M, Montella M; ISDOC Working Group.

Journal of Epidemiology & Community Health. 2007 Jun; 61(6): 547-54.

ABSTRACT

OBJECTIVE: To describe the effect of terminal cancer on the patient's family, finances and daily life. **METHODS:** A cluster sample of 2000 adults (> or = 18 years old) who had died from cancer, and who were representative of Italy, was studied. 1900 caregivers were identified and 68% responded to a post-bereavement survey. Caregivers included the patient's child (46%), his/her spouse (31%), other relatives or friends (20%) or a health professional (3%). The median age of a caregiver was 54 years and 69% were females. During the last 3 months of the patient's life, 44% of caregivers reported difficulties in their regular employment. **RESULTS:** 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. Paying for care was more frequent in the south of Italy (OR 2.5; 95% CI 1.0 to 6.3) and when the patient was a housewife (OR for unit increase 2.7; 95% CI 1.6 to 6.1). To cover the costs of patient care, 26% of families used all or most of their savings. Economic difficulties were greater in the south of Italy (OR 3; 95% CI 1.8 to 5.1), for female caregivers (OR 1.4; 95% CI 1.0 to 1.9) and for disadvantaged patients. The duration of time the patient was completely dependent strongly determined the effect caregiving had on their regular employment and on the family's financial situation. **CONCLUSIONS:** Although in Italy families are responsible for a small percentage of the overall costs of patient care, the effect of cancer on savings and daily life can be substantial. Strong geographical and gender differences emerged from this study.

3. Title: Caregiving at the end of life: perspectives from spousal caregivers and care recipients.

Reference: Jo S, Brazil K, Lohfeld L, Willison K.

Palliat Support Care. 2007 Mar; 5(1): 11-7.

ABSTRACT

OBJECTIVE: The purpose of this study is to examine the perspectives of both the spousal caregiver and care recipient on the caregiving experience in home-based palliative care. **METHODS:** A qualitative research strategy involving home-based face-to-face interviews with older palliative care patients and their spousal caregivers was used to examine the caregiving experience. **RESULTS:** Ten spousal caregivers and care recipient dyads participated in the study. Most informal caregivers viewed caregiving as an extension of the family relationship where caregiving responsibilities evolved over time. Spousal caregivers

identified many negative reactions to caregiving, such as fatigue or weariness, depression, anger and sadness, financial stresses, and lack of time. Care recipients acknowledged the emotional and financial strain and expressed concern for their spouses. Both caregivers and care recipients were appreciative of home care services although they identified the need for additional services. They also identified difficulties in communication with formal providers and poor coordination of care among the various services. Both caregivers and care recipients disclosed some challenges with informal supports, but on the whole felt that their presence was positive. Additional positive aspects of caregiving reported by spouses included strengthened relationship with their spouse and discovering emotional strength and physical abilities in managing care. SIGNIFICANCE OF RESULTS: Health care and social service professionals need to recognize and understand both caregiver and care recipient perspectives if they are to successfully meet the needs of both members of the dyad.

4. Title: What real outcomes matter to caregivers?

Reference: Nurock S, Wojciechowska M.

Int Psychogeriatr. 2007 Jun; 19(3): 355-62.

ABSTRACT

Two surveys of caregivers of people with dementia were conducted in the U.K. and Poland. Among 64 U.K. carers, cognition, early diagnosis and general practitioner support were of particular concern to those caring for people with early dementia, while former carers were more concerned with pain, comfort and palliative issues. There was very strong support for better workforce training. In Poland, restoration of health and more time off from caring were the most desired outcomes.

5. Title: Reducing emotional distress in people caring for patients receiving specialist palliative care. Randomised trial.

Reference: Walsh K, Jones L, Tookman A, Mason C, McLoughlin J, Blizzard R, King M.

The British Journal of Psychiatry. 2007 Feb; 190: 142-7.

ABSTRACT

BACKGROUND: Caring for relatives with advanced cancer may cause psychological and physical ill health. **AIMS:** To evaluate the effectiveness of increased support for distressed, informal carers of patients receiving palliative care. **METHOD:** The sample was composed of 271 informal carers who scored over 5 on the 28-item General Health Questionnaire (GHQ-28). The intervention comprised six weekly visits by a trained advisor. Primary outcome was carer distress (GHQ-28) at 4-week, 9-week and 12-week follow-up. Secondary outcomes were carer strain and quality of life, satisfaction with care, and bereavement outcome. **RESULTS:** Scores on the GHQ-28 fell below the threshold of 5/6 in a third of participants in each trial arm at any follow-up point. Mean scores in the intervention group were lower at all time points but these differences were not significant. No difference was observed in secondary outcomes. Carers receiving the intervention

reported qualitative benefit. **CONCLUSIONS:** The intervention might have been too brief, and ongoing help might have had accruing benefits. Alternatively, informal carers of patients with cancer may already receive considerable input and the advisor's help gave little additional advantage; or caring for a dying relative is extremely stressful and no amount of support is going to make it much better.

6. Title: Characteristics and views of family carers of older people with heart failure.

Reference: Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S, Small N.

Int J Palliat Nurs. 2006 Aug;12(8):380-9.

ABSTRACT

AIMS: to explore the characteristics and views of the family carers of older people with heart failure. **METHOD:** 213 family carers of heart failure patients >60 years were recruited from UK general practitioner (GP) practices. Carer strain, quality of life (QOL) and service satisfaction questionnaires were completed every 3 months for 2 years, as well as 16 interviews with patients and carers, and 9 focus groups with health care professionals. **RESULTS:** 76% of carers were female, 70% were >60 years and 73% were spousal carers. Predictors of carer strain were symptoms of depression, age and patient NYHA. Predictors of lower QOL were: spousal carer; 2+ health conditions and symptoms of depression. Qualitative findings related to the change in circumstances, impact of responsibilities and health conditions of the family carers. **CONCLUSION:** carers were mainly older women, often experiencing multiple health conditions. Addressing the practical and emotional support required presents a challenge for specialist palliative care in responding to calls for increased involvement in heart failure. A shared care model with liaison between specialist heart failure nurses, cardiologists, primary care teams and hospice services is advocated.

7. Title: Problems experienced by the informal caregivers of cancer patients and their needs for support.

Reference: Osse BH, Vernooij-Dassen MJ, Schadé E, Grol RP.

Cancer Nurs. 2006 Sep-Oct; 29(5): 378-88; quiz 389-90.

ABSTRACT

Informal caregivers experience problems of their own for which they need support, but despite the efforts of the World Health Organization to include the well-being of family members and caregivers in the concept of palliative care, their needs are rarely assessed systematically. This report explores caregivers' problems and their needs for professional support. Seventy-six caregivers of cancer patients with advanced disease completed a comprehensive needs assessment questionnaire, the Problems and Needs in Palliative Care questionnaire-caregiver form, listing 67 potential problems in their quality of life and their role of caregiver and 9 items concerning informational needs. The results of this study reveal that the "Top 20" list of the problems and needs reported by caregivers includes fears and emotional burdens; for the most part, caregivers did not need any more professional attention than they were already receiving. Many, however, needed support

for managing patients' symptoms and wanted professional attention for the availability and coordination of services. Despite communalities, there was diversity in caregivers' individual needs. Personal needs could be identified with the Problems and Needs in Palliative Care questionnaire-caregiver form checklist. Although only a few caregivers were affected by some issues, such as financial problems, help for them was often needed. In conclusion, most caregivers would like more professional attention for 4 or 5 specific issues, often related to their competence as caregivers for their patients. Using structured needs assessments with the Problems and Needs in Palliative Care questionnaire-caregiver form seems a feasible method to identify the needs of individual caregivers in palliative care.

8. Title: Primary caregivers of cancer patients in the palliative phase: a path analysis of variables influencing their burden.

Reference: Grov EK, Fosså SD, Sørebo O, Dahl AA.

Soc Sci Med. 2006 Nov; 63(9): 2429-39.

ABSTRACT

Research has shown that several variables influence the burden of primary caregivers of cancer patients staying at home in the palliative phase, but the associations between these variables have hardly been explored. The aim of this study was to examine the associations of theory-driven variables with the caregivers' burden by means of path analysis. The sample consisted of 96 caregivers of cancer patients in the palliative phase staying at home recruited from a hospital trust in Norway. The dimensions of burden from the Caregiver Reaction Assessment, namely self esteem, lack of family support, impact on finances, and impact on daily schedule, were used as the dependent variable. The following independent variables were tested in the models: the patients' levels of pain, fatigue, and nausea; and the caregivers' physical quality of life, anxiety and depression, and social support. The Partial Least Squares approach to structural equation modelling was used for the path analysis. Model 1 shows the direct associations between the independent variables and the dependent variable, explaining 16% of the variance in caregiver burden. Model 1 supports the finding that only caregivers' depression has a direct significant association with caregiver burden, and shows further that the effects of the other independent variables on burden are mediated through depression. In Model 2, anxiety and depression are mediating factors between three other independent variables and caregiver burden, and 12% of the variance is explained. Model 2 supports none of the independent variables as antecedents of burden. Testing of the models suggested that caregivers' depression was the main factor associated with caregiver burden, but also an important mediator of indirect associations of indirect associations of caregivers' anxiety and physical health.

9. Title: A comparison of patients dying at home and patients dying at a hospice: sociodemographic factors and caregivers' experiences.

Reference: Carlsson ME, Rollison B.

Palliat Support Care. 2003 Mar;1(1):33-9.

ABSTRACT

OBJECTIVE: The aim of this study was to investigate whether there were any differences between patients who died at home and patients who died at a hospice, that is, sociodemographic variables, the family caregivers' experiences of burden, and their opinion of reasons for hospice care. **METHODS:** The study comprises a consecutive sample of family caregivers to adult patients: (I) who were cared for by the advanced palliative home care team (APHCT) and died at home, (II) who were cared for by the APHCT and died at the Hospice, (III) who were cared for and died at the Hospice in Uppsala during a period of one year. A questionnaire was mailed to caregivers and the medical records of all the patients were analyzed. **RESULTS:** The place of death differed significantly and varied according to gender and cohabitation status. Men died to a greater degree at home compared with women. The family caregivers' experiences of burden were moderate. Caregivers of patients who died at home thought that this care form has a more positive influence on the patients' quality of life than was the case in the other groups. They were also more satisfied with their own achievement. The caregivers' opinion of why patients needed hospice care was nearly the same in groups II + III, acutely developing symptoms being the most common reason. **SIGNIFICANCE OF RESULTS:** This study showed that women died to a lesser degree at home than men. The explanation for this is unknown and requires further investigation. It is important to establish whether female patients or male caregivers need another type of support than male patients or female caregivers, since the aim of palliative care is that every patient who wishes to die at home should have this wish fulfilled.

10. Title: Participants' experiences of a support group intervention for family members during ongoing palliative home care.

Reference: Milberg A, Rydstrand K, Helander L, Friedrichsen M.

J Palliat Care. 2005 Winter; 21(4): 277-84.

ABSTRACT

The aim of this study was to describe family members' experiences of participation in a support group intervention during ongoing palliative home care. Four taped-recorded focus group interviews were conducted (in total, 13 persons) and a questionnaire was completed by 19 of 22 possible family members. The participants experienced increased perception of support and knowledge, and would recommend that a person in a similar situation join a support group. Categories that emerged in the qualitative content analysis concerned "reasons for support group participation", "group composition contributed to group cohesion", "experience and sensitivity of group leader was a catalyst", "meaningful dialogue helped to solve everyday problems", "sense of cohesion increased effectiveness of

the group", and "group sessions and post-session reflection increased perception of inner strength". Support groups for family members seem to be a valuable contribution during ongoing palliative home care. The findings are discussed in relation to recruitment into and ending of support groups.

11. Title: A burden to others: a common source of distress for the terminally ill.

Reference: Wilson KG, Curran D, McPherson CJ.

Cogn Behav Ther. 2005;34 (2):115-23.

ABSTRACT

Recent research into the desire for death among people with terminal illness has begun to recognize the importance of "feeling oneself a burden to others" as a factor in suicidal behaviour. In this study, 69 patients with advanced cancer underwent semi-structured interviews. The sense of self-perceived burden was found to be a common experience, reported by 39.1% of participants as a minimal or mild concern and by 38% as a moderate to extreme concern. The sense of burden showed a low correlation with physical symptoms ($r = 0.02-0.24$) and higher correlations with psychological problems ($r = 0.35-0.39$) and existential issues ($r = 0.45-0.49$). Comparisons of participants with high or low levels of self-perceived burden showed the importance of this factor for overall quality of life. In summary, self-perceived burden is an important but underestimated dimension of social cognition in the medically ill.

12. Title: Strain experienced by caregivers of dementia patients receiving palliative care: findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program.

Reference: Diwan S, Hougham GW, Sachs GA.

J Palliat Med. 2004 Dec; 7(6): 797-807.

ABSTRACT

BACKGROUND: Programs that provide palliative care to individuals with dementia, which is a progressive terminal illness, are likely to encounter different issues (e.g., management of problem behaviors, caregiver strain extending over years) from those typically addressed by hospice programs. Little research is available on palliative care for individuals with dementia who live in the community. **OBJECTIVE:** This study examines predictors of types of strain experienced by caregivers of community-dwelling patients with dementia enrolled in a unique demonstration program titled Palliative Excellence in Alzheimer Care Efforts (PEACE), which moved palliative care "upstream," integrating palliative care into the primary care of patients with dementia. **DESIGN:** Data were collected through structured, face-to-face interviews with 150 community-dwelling, predominantly African American patient-caregiver dyads who were enrolled in the PEACE program. **Measurements:** Established measures, including the Caregiver Strain Index, the Revised Memory and Behavior Problems Checklist, and the Katz Index of Activities of Daily Living, were used in addition to other measures assessing caregiver, patient, and situational characteristics. **RESULTS:** Factor analysis of the Caregiver Strain Index

revealed three dimensions of strain (role, personal, and emotional) related to caregiving. Using a stress process model, regression analyses examined stressors and resources related to patient, caregiver, and support system characteristics in predicting these three dimensions of strain among caregivers. Patient problem behaviors predicted all types of caregiver strain. Perceived lack of support from the health care team predicted personal and emotional strain, whereas higher income, surprisingly, predicted role strain. Patient functional limitations predicted personal and role strain. **CONCLUSIONS:** Findings suggest that effective palliative care programs for patients with dementia need to understand and address the various sources and types of caregiver strain; provide adequate support to caregivers for the management of problem behaviors; provide counseling to help cope with the emotional reactions to the cognitive and behavioral changes associated with dementia progression; facilitate communication with the health care team; and broker access to community and other resources for assistance with functional limitations. Further research examining changes in strain over time will provide useful insights on the delivery of care and services for patients with dementia and their families in a palliative care framework.

13. Title: Advanced cancer at home: caregiving and bereavement.

Reference: Rossi Ferrario S, Cardillo V, Vicario F, Balzarini E, Zotti AM.

Palliat Med. 2004 Mar;18(2):129-36.

ABSTRACT

BACKGROUND: The advanced and terminal phases of cancer are being increasingly treated at home with the aid of palliative care teams. It is well known that caregivers are overburdened emotionally, financially and physically, and some studies have demonstrated that this overload extends beyond the period of mourning. Identifying caregivers at risk of bereavement maladjustment is a useful means of ensuring prompt psychological and social assistance, and optimising the available resources. **METHODS:** One hundred and eleven caregivers of home-treated patients with advanced/terminal cancer were recruited by the palliative care unit operating in their place of residence. After giving their informed consent, all of the caregivers were asked to complete questionnaires designed to evaluate various emotional, financial and social aspects. Three, six and 12 months after the decease of their patients, the caregivers were contacted again and asked to complete other questionnaires aimed at assessing their emotional reactions and bereavement-related problems. **RESULTS:** The 12-month follow-up was completed by 93 caregivers. Their bereavement maladjustment problems correlated with their perception of emotional distress and the caregiving-related problems detected at the time of referral, particularly among females. Spouses, subjects aged over 61 years and those perceiving a substantial emotional burden proved to be at greater long-term risk. **CONCLUSIONS:** The identification of overburdened caregivers and those at risk of long-term bereavement maladjustment may facilitate the programming of ad hoc interventions that could reduce inherent health and social costs. Palliative care teams can usefully include someone to identify such caregivers by means of inexpensive and objectively predictive instruments.

14. Title: Caregiving and its impact on families of the terminally ill

Reference: Brazil K, Bédard M, Willison K, Hode M.

Aging Ment Health. 2003 Sep; 7(5): 376-82.

ABSTRACT

Changes in the health care system have meant that increasing numbers of the terminally ill receive the majority of their care at home. The purpose of this paper was to document patterns of informal and formal care provided to the terminally ill and assess the impact caregiving has on family members. One hundred and fifty-one family caregivers were recruited for interviews from two community-nursing agencies in an urban region of the province of Ontario, Canada. The majority of respondents 119 (79%) were the female spouses of the patient. The numbers of caregivers providing assistance in specific functional activities were: bathing, 133 (88%); mobility, 123 (81%); dressing and undressing, 114 (76%); toileting, 101(67%), and assistance at night 97 (64%). Sixty-two (41%) respondents reported that they had been providing some form of caregiving for over one year. They also reported that physical demands in caregiving increased substantially during the last three months of the care recipient's life. As family caregivers provided more assistance in activities of daily living they were at greater risk of reporting high caregiver burden. The results of this paper identify the types of care provided by family caregivers of the terminally ill and the impact these demands have on the family caregiver.

15. Title: Family involvement in end-of-life hospital care.

Reference: Tschann JM, Kaufman SR, Micco GP.

J Am Geriatr Soc. 2003 Jun; 51(6): 835-40.

Comment in:

J Am Geriatr Soc. 2004 Jun;52(6):1027-8; author reply 1028.

ABSTRACT

OBJECTIVES: To examine whether the end-of-life treatment provided to hospitalized patients differed for those who had a family member present at death and those who did not. **DESIGN:** A retrospective cohort analysis. **SETTING:** An urban community hospital. **PARTICIPANTS:** All 370 inpatients who died during a 1-year period. **MEASUREMENTS:** Medical records were examined for whether life-support treatments were provided or withdrawn, occurrence and timing of do-not-resuscitate (DNR) orders, and use of comfort measures such as narcotics and sedation. **RESULTS:** DNR orders were written for 85% of patients. For patients who had a DNR order written, the average time from the DNR order to death was 4.8 days. Only 26% of patients had one or more treatments withdrawn. Sixty-seven percent of patients received narcotics before death, and 22% received sedatives. Patients aged 75 and older and African Americans were less likely to have a family member present at death. After adjusting for age and ethnicity, patients who had a family member present at death were more likely to have DNR orders written, to have treatments withdrawn, and to receive narcotics before death. Patients with a family member present at death also had a shorter time to death after DNR orders were written.

CONCLUSION: The presence of a family member at death appears to be an indirect measure of family involvement during patients' hospitalization. Family involvement before death may reduce the use of technology and increase the use of comfort care as patients die.

16. Title: Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity.

Reference: Proot IM, Abu-Saad HH, Crebolder HF, Goldsteen M, Luker KA, Widdershoven GA. *Scand J Caring Sci.* 2003 Jun; 17(2): 113-21.

ABSTRACT

This paper reports on a grounded theory interview-based study with 13 family members aged 28-80 years caring for terminally ill people at home (with a life expectancy of 3 months or less) in the Netherlands. The project was approved by the ethics committee of the Maastricht University Hospital. The aim of this study was to explore the experiences of family caregivers, their needs for home care, and which health services they receive. Data were analysed using the constant comparative method. 'Vulnerability' was identified as the core category. Caring for a terminally ill person at home requires continuous balancing between care burden and capacity to cope. Whether or not the carer will succeed in keeping in optimum balance is dependent on a number of factors impinging on the caregiver's vulnerability. Care burden, restricted activities, fear, insecurity, loneliness, facing death, lack of emotional, practical and information-related support were identified from the data as factors having the potential to increase the caregiver's vulnerability, and may be risk factors for fatigue and burnout. Continuing previous activities, hope, keeping control, satisfaction and good support are factors which may decrease the caregiver's vulnerability, and may protect against fatigue and burnout. The experiences of the caregivers in our study showed that the support from informal and professional caregivers was not sufficient. Education and practical tools may make professionals more sensitive for the vulnerable position of family caregivers, even when these caregivers do not show their vulnerability.