

Centre for Policy on Ageing
Information Service

Selected Readings

**Palliative Care of Older
People**

June 2010

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2009

Benchmarking analysis: needs resourcing, outputs and outcomes of palliative and end of life care; by Peter Tebbit, National Council for Palliative Care - NCP. London: National Council for Palliative Care, November 2009, 26 pp.

The 'End of life care strategy' published by the Department of Health (DH) in 2008 sets out the information that should be readily available on end of life care, on which the National Council for Palliative Care (NCP) contributes this document. The starting point for benchmarking is the Index of Differential Population Need for Strategic Health Authority (SHA) and PCT populations published in 'Population-based needs assessment for palliative and end of life care: a compendium of data for strategic health authorities and primary care trusts' (2008). 'Benchmarking analysis' aims to fill gaps in the 'End of life care strategy' by presenting headline data on institutional care and the financial resources available at SHA level. Source data is presented on: indices of comparative palliative and end of care need; specialist palliative care bed provision and its use; care home capacity; numbers of deaths and place of occurrence; and expenditure on specialist palliative care services by NHS and voluntary services. Each table is accompanied by explanatory notes, comments on interpretation of each index, and commentary on the variation in need between areas. (RH)

Price: £10.00 (free to NCP subscribers)

From : National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS. E-mail: enquiries@ncpc.org.uk Website: www.ncpc.org.uk

Bereaved informal cancer carers making sense of their palliative care experiences at home; by W K Tim Wong, Jane Ussher.

Health and Social Care in the Community, vol 17, no 3, May 2009, pp 274-282.

This qualitative study explored the positive meanings constructed and ascribed to the experiences of providing palliative care at home by bereaved informal cancer carers, a group of individuals who are in a position to make sense of their caring experiences as a coherent whole. 22 bereaved cancer carers in New South Wales (NSW), Australia were recruited through cancer support groups, cancer clinics and the Cancer Council NSW. They were interviewed as part of a larger mixed-method study examining the experience of informal cancer care. The findings indicated that these bereaved carers gave accounts that accentuated the benefit and satisfaction derived from providing direct palliative care at home, which enabled them to construct positive meanings associated with their participation in the dying process, and as a result to ascribe subjectively meaningful interpretations to their loved ones' death and their sense of loss. This included a sense of reward for doing something good, meeting the expressed needs of the patient, continuing with normal life as much as possible, improving the condition of the relationship, and meeting cultural expectations of the right thing to do. Being present at the point of death was positioned as rewarding because it facilitated the process of saying goodbye, fostered inclusion of others, provided closure and was as spiritual experience. These findings suggest that there are positive and rewarding aspects associated with providing informal cancer care in a palliative context, and these aspects were pertinent and meaningful for carers in their endeavours to reconcile the difficulties and loss they experienced. This has implications for the prevention and amelioration of distress experienced by informal cancer carers, and suggests that future research should not ignore the positive aspects of providing palliative care. (RH)

ISSN: 09660410

From : <http://www.blackwellpublishing.com/hsc>

Better care every step of the way: report on the quality of palliative and end of life care in care homes for adults and older people; by Scottish Commission for the Regulation of Care (Care Commission). Dundee: The Care Commission, April 2009, 28 pp (Ref: IHD/006/0109).

A national action plan, 'Living and dying well' (Scottish Government, 2008), sets out a plan for delivery of high quality palliative and end of life care for everyone who needs it across all care settings in Scotland. This report aims to raise awareness of the need for such care in all care homes. Inspections showed that 587 (57%) of the care homes in the sample understood the importance of this; and this report includes examples of good practice. However, a sizeable minority of care homes fell short on aspects of best practice in respect of recognising need and in providing training around sensitive issues surrounding death and dying. The report also includes what was learned from complaints about palliative and end of life care, and makes recommendations about such provision. (RH)

From : Download

(16/6/09):http://www.carecommission.com/images/stories/documents/publications/reviewsofqualitycare/better_care_every_step_of_the_way_-_april_2009.pdf

Developments in end-of-life and palliative care social work: international issues; by Malcolm Payne.
International Social Work, July 2009, pp 513-524.

Palliative care social work has developed primarily as a specialist health-related form of clinical social work. However, the resource-intensive modernist medicalized practice of Western countries has been culturally inappropriate elsewhere. Broader end-of-life care and community education outside healthcare settings offers opportunities to develop palliative care social work in the direction of social development practice. (KJ/RH)
ISSN: 00208728

From : <http://isw.sagepub.com>

Dying old in the 21st century: a neglected issue for social work; by Margaret Holloway.
International Social Work, November 2009, pp 713-725.

Dying in old age has become the majority dying of the developed world, yet older people are routinely denied palliative care, their dying characterized by failure to facilitate choice and recognize their needs. Social workers in all settings should embrace their contribution to quality end-of-life care for older people. (KJ/RH)
ISSN: 00208728

From : <http://isw.sagepub.com>

Minimum data sets for palliative care: 2007/08 project update; by National Council for Palliative Care - NCPC.
London: National Council for Palliative Care - NCPC, 2009, 7 pp.

In 1995, the NCPC in collaboration with the Department of Health (DH) developed a minimum data set (MDS) for palliative care. This bulletin updates the review work undertaken so far, which has led to a revision of the questionnaires used to produce the MDS (which can be found on the NCPC website). The bulletin includes the findings from the 2007-8 National Data Collection and gives comparisons with previous years. The findings relate to data received from inpatient units, day care units, home care services, hospital support services, and out-patient services in response to a questionnaire (78% overall response rate). A fuller report is available from the NCPC, and available for subscribers to download in the Online Library (at www.ncpc.org.uk). (RH)

Price: £7.00

From : NCPC, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.<http://www.ncpc.org.uk>

Palliative care training; by Catriona Curry, Heather Middleton, Bob Brown.
Nursing Older People, vol 21, no 9, November 2009, pp 18-23.

Practice development has proved effective in changing culture and practice in end-of-life care in two Northern Ireland nursing homes. The authors discuss a project that explored and resolved the palliative care education needs of staff. The practice development framework has enhanced the provision of palliative care to residents in both homes, and provided ongoing training and awareness sessions for staff. (RH)

ISSN: 14720795

From : <http://www.nursingolderpeople.co.uk>

Places for palliative care; by Debra Parker Oliver, Benyamin Schwarz (et al.): The Haworth Press, Inc., 2009, 129 pp (whole issue).

Journal of Housing for the Elderly, vol 23, nos 1-2, 2009, 129 pp (whole issue).

This special issue of Journal of Housing for the Elderly explores some places in which hospice and palliative care is provided in the US and the UK, also what constitutes a "good death". These "places" for palliative care range from the situations of older homeless people and the public nature of acute hospital settings, to assisted living, houses with modified interiors, "smart homes", and generally making provision in the home environment. (RH)

ISSN: 02763893

From : Taylor & Francis Group, 325 Chestnut Street, Philadelphia, PA 19106, USA. email: haworthpress@taylorandfrancis.com(www.taylorandfrancis.com)

The power of partnership: palliative care in dementia; by Lynn Gibson, Julian Hughes, Alice Jordan (et al), National Council for Palliative Care - NCPC; for dementia; Alzheimer's Society. London: National Council for Palliative Care - NCPC, December 2009, 35 pp.

This discussion document strongly endorses a partnership between dementia care and palliative care services as a means of improving the care of people with dementia at the end of life. It considers: the progressive nature of dementia and its impact on cognition; the challenges of advanced dementia such as advance care planning and identifying the time of transition towards more palliation; and helping people with dementia and their families. It describes four examples of partnerships between palliative care and dementia. The aim is to stimulate further discussion amongst all health and social care staff involved with the person with dementia and carers, and to

highlight gaps in knowledge and the need for education in both palliative and dementia care services, such that as many questions are asked as are answered. (RH)

Price: £15 (free to subscribers)

From : NCPC, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.<http://www.ncpc.org.uk>

Resilience and vulnerability to chronic pain: conceptual and methodological issues; by Anthony D Ong, M Carrington Reid, Elaine Wethington (et al).

Signpost, vol 13, no 3, February 2009, pp 24-25.

How do older people in general and those with dementia in particular qualitatively experience, accurately report, and adapt to chronic pain? Researchers into resilience aim to identify vulnerability and protective factors that might modify negative effects. This article presents a short review of the evidence. (RH)

ISSN: 13684345

From : <http://www.signpostjournal.co.uk>

Transforming research into action: a European Parliament report on palliative care; by Jose M Martin-Moreno, Meggan Harris, Lydia Gorgojo (et al).

Eurohealth, vol 15, no 2, 2009, pp 23-25.

The authors of a European Parliament report on palliative care summarise the process of the five-month investigation, as well as the real and potential results of the study. Engaging a large number of national and international stakeholders, including ministries of health, national palliative care associations and the European Association for Palliative Care (EAPC), the authors were able to draw on a well of previous research and diverse experiences before formulating operative policy options for the European Union (EU) and its Member States. While the report itself fomented some self-examination in the countries studied, its full exploitation by palliative care advocates is still pending. (KJ/RH)

ISSN: 13561030

From : <http://www2.lse.ac.uk/LSEHealthAndSocialCare/LSEHealth/Home.aspxeurohealth@lse.ac.uk>

2008

Development of palliative care and legalisation of euthanasia: antagonism or synergy?; by Jan Bernheim, Reginald Deschepper, Wim Distelmans (et al).

British Medical Journal, vol 336 no 7649, 19 April 2008, pp 864-867.

Debates about euthanasia often polarise opinion, but in Belgium the two sides have been mutually reinforcing: advocates for the legalisation of euthanasia work in palliative care and vice versa. Belgium was the second country to legalise euthanasia but also has among the best developed palliative care, and the authors outline milestones in the development of both. Adequate palliative care has made the legalisation of euthanasia ethically and politically acceptable. (RH)

ISSN: 09598138

From : <http://www.bmj.com>

Exploring non-medical prescribing in palliative care; by Lucy Sutton, Ross Carroll, National Council for Palliative Care - NCPC; Help the Hospices. London: National Council for Palliative Care, March 2008, 17 pp.

Non-medical prescribing (NMP) relates to any prescribing that is undertaken by a health care professional who is not a doctor or dentist. A survey by the National Council for Palliative Care (NCPC) assessing issues around NMP in palliative care has prompted further investigation by NCPC. This publication outlines the survey results and the issues affecting NMP and specialist palliative care, for example: training and support; mentorship; access to records; and medical reluctance. The benefits of introducing NMP are summarised, and some local and national recommendations are made. (RH)

Price: £15.00

From : National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS. E-mail: enquiries@ncpc.org.uk Website: www.ncpc.org.uk

Exploring the interface: a survey of neurology nurses' involvement with specialist palliative care services and identification of their training needs; by Jane Bridger, Lucy Sutton, Sue Thomas, Neurological Conditions Policy Group, National Council for Palliative Care - NCPC; Neuroscience Forum, Royal College of Nursing - RCN. London: National Council for Palliative Care - NCPC, 2008, 31 pp.

The National Service Framework for Long Term Conditions (NSF LTC) advocates life-long care for people with long-term neurological conditions (LTNC), and specifically notes the need for specialist neurology, rehabilitation and palliative care services at the end of life. Following on from the report, 'Focus on neurology: addressing palliative care for people with neurological conditions', this survey develops this work further. The

Neurological Conditions Policy Group of NCPC undertook the survey neurology nurses in partnership with the RCN Neuroscience Forum, to assess current involvement with, and perceptions of, palliative care services for people with long-term neurological conditions (LTNC). Of 429 questionnaires sent, 90 were returned (21%) and 88 analysed. Findings are presented regarding work settings, criteria for and guidelines on referrals, the value of a palliative care pathway for those with LTNC, training needs, and using tools and pathways to facilitate palliative and end of life care. Recommendations are made on these issues, also on opportunities for joint working. (RH)

Price: £15.00 (free to subscribers)

From : NCPC, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.<http://www.ncpc.org.uk>

Family members providing home-based palliative care to older adults: the enactment of multiple roles; by Sarah J Clemmer, Catherine Ward-Griffin, Dorothy Forbes.

Canadian Journal on Aging, vol 27, no 3, Fall 2008, pp 267-284.

Canadians are experiencing increased life expectancy and chronic illness requiring end-of-life care. Based on a larger ethnographic study of client-family-provider relationships in home-based palliative care, this qualitative secondary analysis explores the enactment of multiple roles for family members providing home-based palliative care to seniors with advanced cancer. Family members had multiple expectations to provide care, but felt that expectations of services were unmet. The process of enacting multiple roles was depicted by three interrelated themes: balancing, re-prioritising, and evolving. Positive and negative health responses resulted from attempts to minimise personal health while simultaneously maintaining health. "True" family-centred care was found to be lacking, but should be a goal of health professionals involved in end-of-life care. (KJ/RH)

ISSN: 07149808

From : <http://www.utpjournals.com>

German community pastors' contact with palliative care patients and collaboration with health care professionals; by Kurt Buser, Volker E Amelung, Nils Schneider. Binghamton, NY: Haworth Social Work Practice Press, 2008, pp 85-100.

Journal of Social Work in End-of-life & Palliative Care, vol 4, no 2, 2008, pp 85-100.

The current level of palliative care in Germany is unsatisfactory. Health care professionals view the psychological support of patients and families and the collaboration between different care providers as the main deficiencies. In this context, community pastors could have an important role in providing psychosocial and spiritual care of patients at home, but little is known of their views on this matter. The authors conducted 76 standardised telephone interviews with protestant and Catholic pastors and examined how much contact pastors had with palliative care patients, their views on collaborating with health care professionals, and how pastors assessed their own skills in palliative care. 41% of respondents had no contact with any palliative care patients. The majority perceived collaboration with family doctors to be insufficient. The pastors assessed their own skills concerning palliative care predominantly as "satisfactory". The findings suggest that community pastors' participation in delivering palliative care in Germany might be encouraged by specialised training and intensified contact with health care professionals. (RH)

ISSN: 15524256

From : Taylor & Francis Group, LLC, 325 Chestnut Street, Philadelphia PA 19106, USA.www.tandf.co.uk/journals

Lessons in life and death from a poor relation: [palliative care]; by Lianne Downey.

Professional Social Work, October 2008, pp 22-23.

A newly-qualified social worker who trained specifically to return to the world of palliative care where she was previously a care workers questions why this area of the profession struggles to be taken seriously by others, including social workers. She feels very strongly that social work interventions can enhance the end-of-life care that everyone should receive. Social workers can and must be better prepared to work with loss, dying and bereavement. The changing nature of social work education offers a clear opportunity to emphasise the importance of palliative care. (RH)

ISSN: 13523112

Listening to the experts: a summary of 'User involvement in palliative care: a scoping study'; by Sian Maslin-Prothero, Helen Findlay (eds), Service User Advisory Group, National Council for Palliative Care - NCPC; Lancaster University; St Christopher's Hospice. London: National Council for Palliative Care, May 2008, 27 pp. This document is an edited version of 'User involvement in palliative care: a scoping study', which was funded by St Christopher's Hospice in 2004, and can be found on the NCPC website (www.ncpc.org.uk). The Service User Advisory Group (SUAG) at the NCPC recognised the need for this document to be brought up to date, placed in the public domain, and in an accessible format. Sian Maslin-Prothero and Helen Findlay from the

SUAG worked with Professor Sheila Payne and colleagues to edit and update the original report for 2008. User involvement is widely promoted within health and social care policy as an effective means of developing patient-centred services. This report is predominantly concerned with the development of user involvement initiatives in relation to services rather than research. It outlines the findings of a literature search in three ways: bibliometric analysis, an annotated bibliography, and qualitative content analysis. The views of key informants obtained using face-to-face or telephone interviews are presented, and confirm an increasing level of activity in relation to user involvement in palliative care. (RH)

Price: £15.00

From : National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS. E-mail: enquiries@ncpc.org.uk Website: www.ncpc.org.uk

Multiple conditions: multiple challenges: exploring palliative and end of life care for older people with multiple conditions; by Lucy Sutton, Philip Hurst, National Council for Palliative Care - NCPC; Age Concern England - ACE; Help the Aged. London: National Council for Palliative Care, October 2008, 23 pp.

Frail older people with multiple conditions make the greatest use of the health and social care system. In order to better meet this group's palliative care needs, staff must be encouraged to consider the whole person throughout the care process. This guidance publication is designed to support implementation of the End of Life Care Strategy. It uses innovative practice examples and case studies of inappropriate care to illustrate how best to achieve individual centred care and commissioning of services. It makes recommendations on workforce training and development. Content of this publication was informed by a roundtable discussion on the topic in November 2007 and a national event, 'Dying with Dignity' in March 2008. (RH)

Price: £15.00

From : National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS. E-mail: enquiries@ncpc.org.uk Website: www.ncpc.org.uk

Population-based needs assessment for palliative and end of life care: a compendium of data for strategic health authorities and primary care trusts; by Peter Tebbit, National Council for Palliative Care - NCPC. [2nd ed] London: National Council for Palliative Care, May 2008, 50 pp.

This compendium comprises tables of comparative end of life care needs for primary care trusts (PCTs), cancer networks and strategic health authorities (SHAs). It presents data from four sources: mortality statistics from the Health and Social Care Information Centre's Compendium of clinical health indicators; mid-2005 population estimates for local authorities (Office for National Statistics - ONS); the Index of Multiple Deprivation (MD2004); and the Department of Health (DH) published description of the 152 PCTs and 10 SHAs. Each table is accompanied by explanatory notes, comments on interpretation of each index, and commentary on the variation in need between areas. (RH)

Price: £25.00

From : National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS. E-mail: enquiries@ncpc.org.uk Website: www.ncpc.org.uk

2007

Death denial: obstacle or instrument for palliative care?: an analysis of clinical literature; by Camilla Zimmermann.

Sociology of Health & Illness, vol 29, no 2, March 2007, pp 297-314.

As a society and as individuals, we have come to recognise ourselves as 'death-denying', a self-characterisation particularly prominent in palliative care discourse and practice. As part of a larger project examining death attitudes in the palliative care setting, a Medline search (1971 to 2001) was performed combining the text words 'deny' and 'denial' with the subject headings 'terminal care', 'palliative care' and 'hospice care'. The 30 articles were analysed using a constant comparison technique, and emerging themes regarding the meaning and usage of the words deny and denial were identified. This paper examines the theme of denial as an obstacle in palliative care. In the articles, denial was described as an impediment to open discussion of dying, dying at home, stopping 'futile' treatments, advance care planning, and control of symptoms. The author suggests that these components of care together constitute what has come to be perceived as a correct 'way to die'. Indeed, the very conceptualisation of denial as an obstacle to these components of care has been integral to building and sustaining the 'way to die' itself. The personal struggle with mortality has become an important instrument in the public problem of managing the dying process. (RH)

ISSN: 01419889

From : <http://www.blackwellpublishing.com>

Exploring the palliative and end-of-life care needs of those affected by progressive long-term neurological conditions; by Eleanor Wilson, Jane Seymour. London

Journal of Care Services Management, vol 2, no 1, October-December 2007, pp 92-102.

Currently, there is a new policy focus on the palliative and end-of-life care needs of people with progressive long-term neurological conditions (PLINC). Perhaps because of the comparative rarity of these diseases - which often have long and unpredictable trajectories - little dialogue has taken place to date about the associated care needs. This paper reviews some of the key challenges raised in providing care for people with PLINC, highlighting the complex problems faced by people affected by these conditions and the challenges these pose for care delivery in the community. In reviewing the literature and policy documents, it is clear that there is wide scope for further research. The authors conclude with an overview of a study currently being undertaken at the University of Nottingham to explore these issues further. The aim of the study is to work collaboratively with health and social care professionals working with service users with advanced neurological conditions (especially Huntington's disease) and their carers to develop recommendations for best practice and insights into the applicability of interventions to enhance palliative and end-of-life care within this client group. (RH)

ISSN: 17501679

From : <http://www.henrystewart.com>

Faith, dying and palliative care in multicultural Britain; by Alison South, Elizabeth Teale, Victoria Watts.

Geriatric Medicine, vol 37, no 4, April 2007, pp 17-22.

We live in an increasingly diverse society, both culturally and religiously. Rituals surrounding dying and death differ between faiths. To provide appropriate end-of-life care, it is essential that healthcare workers have an understanding of the practices and beliefs of patients and their families. This article outlines the basic principles for the major religions in the UK: Christianity, Islam, Hinduism, Sikhism, Judaism, and Buddhism. (RH)

ISSN: 0268201X

Focus on neurology: addressing palliative care for people with neurological conditions; by Lucy Sutton (comp), Neurological Conditions Policy Group, National Council for Palliative Care - NCPC. London: National Council for Palliative Care - NCPC, 2007, 31 pp.

The Neurological Conditions Policy Group of NCPC was established to: identify the palliative care needs of people with neurological conditions; map and assess the adequacy of current provision; identify good practice; and identify service models to meet these needs. This study describes existing access to specialist palliative care (SPC) services for people with long-term neurological conditions (LTNC); identifies gaps in service provision; identifies the views of consultants in the specialities of palliative medicine, rehabilitation and neurology regarding their own and other specialities' roles, access to services and any gaps; and determines how their services should interact to meet the needs of people with LTNC. The publication has been produced with support from the Parkinson's Disease Society and Big Lottery Fund. (RH)

Price: £15.00

From : NCPC, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.<http://www.ncpc.org.uk>

Holistic common assessment of supportive and palliative care needs for adults with cancer: assessment guidance; by Alison Richardson, Peter Tebbit, Vivienne Brown (et al), Cancer Action Team, Department of Palliative Care, St Thomas' Hospital; King's College London. London: Cancer Action Team, January 2007, 21 pp.

This guidance has been prepared in response to Key Recommendation 2 in "Guidance on cancer services: improving supportive and palliative care for adults with Cancer: the manual" (National Institute for Clinical Excellence, NICE, 2004). The guidance is for practitioners and managers providing or co-ordinating care of adults with cancer, to enable a unified approach to the assessment and recording of patients' needs. It is designed for healthcare teams to employ as a benchmark against which current local processes of assessment can be appraised. This document sets out the main features of the holistic assessment and provides the core content of the assessment. (RH)

From : Cancer Action Team, Department of Palliative Care, St Thomas' Hospital, Lambeth Palace Road, London SE1 7EH. Also available at: www.dh.gov.uk/cancer

Holistic common assessment of supportive and palliative care needs for adults with cancer: report to the National Cancer Action Team; by Alison Richardson, Peter Tebbit, Vivienne Brown (et al), Cancer Action Team, Department of Palliative Care, St Thomas' Hospital; King's College London. London: King's College London, January 2007, 38 pp.

The National Institute for Clinical Excellence (NICE) publication "Guidance on cancer services: improving supportive and palliative care for adults with Cancer: the manual" identified barriers in service provision for patients and carers. This report describes the methods used to develop and test a national specification for the

assessment process in supportive and palliative care, and presents the underlying philosophy and principles on which it is based. It also sets out the framework employed to develop the detailed guidance for healthcare teams. Annex 1 notes the interface with current and future policy initiatives: the Integrated Cancer Care Programme; Skills for Health; Connecting for Health (including the Do Once and Share programme, DOAS); the Common Assessment Framework (CAF, building on the Single Assessment Process, SAP); and the End of Life Care Initiative. Annex 4 outlines the methods used to develop item content for domains of need, and lists tools identified in the original scoping exercise. (RH)

From : Cancer Action Team, Department of Palliative Care, St Thomas' Hospital, Lambeth Palace Road, London SE1 7EH. Also available at: www.dh.gov.uk/cancer

Home-based palliative care in Sydney, Australia: the carer's perspective on the provision of informal care; by Saggi Zapart, Patricia Kenny, Jane Hall (et al).

Health and Social Care in the Community, vol 15, no 2, March 2007, pp 97-107.

The provision of home-based palliative care requires a substantial unpaid contribution from family and friends (i.e. informal care). This cross-sectional descriptive study, conducted between September 2003 and April 2004, describes the contribution and impact it has on those providing informal care. Participants were 82 informal carers of patients registered with two community palliative care services in Sydney, Australia (40% of eligible carers). Carers were interviewed to assess the care recipient's care needs, the care provided by the informal carer, and the health status of the carer (using the 36-item Short Form Health Survey, SF-36). A number of open-ended questions asked about the impact of providing care and the type of support that carers would find helpful. Most carers reported that care recipients required help with household tasks; and many needed assistance with personal activities of daily living (ADLs), taking medications, and organisational tasks. In the majority of cases, the principal carer provided all or most of this help. Although on average the physical health of carers was similar to that of the Australian population, their mental health scores were lower. Many carers reported effects on social and family relationships, restrictions on their participation at work and leisure activities, and a range of emotional reactions to their caring situation. The support carers said they would like included information and advice, in-home respite, help with household tasks, and financial support. This study supports the view that effective support for carers must recognise the pre-existing relationship between carer and recipient, and the differing needs of individual carers. (RH)

ISSN: 09660410

From : <http://www.blackwellpublishing.com/hsc>

Medicine, care of the dying, and care of the chronically ill; by Milton Lewis.: LSE Health; European Observatory on Health Systems and Policies, 2007, pp 14-16.

Eurohealth, vol 13, no 2, 2007, pp 14-16.

The palliative care movement began in Great Britain and spread quickly, not only to the United States, Australia, Canada and New Zealand but also to continental Europe. This article provides an overview of material covered in a new book entitled "Medicine and care of the dying: a modern history" (Lewis; OUP, New York, 2007). Historically, concern about palliative care has developed separately from that about better care for the chronically ill; but the same demographic and other forces are now shaping the context in which more patient-centred services are needed. Palliative care and care for the chronically ill should be better integrated, as should health services generally. (KJ/RH)

ISSN: 13561030

From : <http://www.lse.ac.uk/LSEHealtheurohealth@lse.ac.uk>

Minimum data sets for specialist palliative care: project update including 2006-07 data; by National Council for Palliative Care - NCPC. London: National Council for Palliative Care - NCPC, 2007, 7 pp.

In 1995, the NCPC in collaboration with the Department of Health (DH) developed a minimum data set (MDS) for palliative care. A standard data collection questionnaire was developed and used in England, Wales and Northern Ireland. After twelve years of using this questionnaire, in 2005/06 NCPC commissioned the Marie Curie Palliative Care Institute Liverpool to review the minimum data set questionnaires, to examine whether current data items are still relevant and appropriate, and what new data should be collected. This bulletin updates the review work undertaken so far, which has led to a revision of the questionnaires used to produce the MDS. The new updated MDS for 2008/9 are now available from the NCPC website and should be used from April 2008. This bulletin also includes the findings from the 2006-7 National Data Collection and gives comparison with previous years. These findings relate to data received from inpatient units, day care units, home care services, hospital support services, and out-patient services in response to a questionnaire (80% response rate). (KJ/RH)

Price: £10.00

From : NCPC, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.<http://www.ncpc.org.uk>

Palliative care and the Mental Capacity Act; by Simon Chapman, Nick Hayes.

Working with Older People, vol 11, issue 1, March 2007, pp 21-24.

The impact of the Mental Capacity Act 2005 is examined from a palliative care perspective. The authors comment on ways in which the Act will hopefully bring more clarity in assessing a person's best interests with regard to: the role of relatives; advance care planning; living wills; and proxy decision-making. (RH)

ISSN: 13663666

From : (Fuller information on the Act can be obtained from : www.dca.gov.uk/legal-policy/mental-capacity/index.htm)

Palliative care for dementia sufferers; by Social Care Institute for Excellence - SCIE.

Community Care, issue 1695, 18 October 2007, pp 38-39.

The Social Care Institute for Excellence (SCIE) presents a few facts and figures on the effects of dementia, and points to sources such as the SCIE/NICE Guidelines on dementia, the NHS End of life programme (www.endoflifecare.nhs.uk) and the National Council for Palliative Care (www.ncpc.org.uk). Short abstracts on five recent items are included: 'An integrated approach to dementia care', by Kim Y Kye and Brian E Wood (Dementia: an international journal of social research and practice, vol 6, no 2, May 2007); 'End-of-life decision making for nursing home residents with dementia: a survey of nursing home social services staff', by Debra Lacey (Health and Social Work, vo 31, no 3, August 2006); 'Palliative care in severe dementia in association with nursing and residential care', by Julian Hughes (MA Healthcare, 2006); 'Exploring palliative care for people with dementia: a discussion document' (NCPC, 2006); and 'Ethical foundations of palliative care for Alzheimer's disease', by Ruth Purtilo and Henk Have (Baltimore, MD: Johns Hopkins University Press, 2004). (RH)

ISSN: 03075508

From : <http://www.communitycare.co.uk>

Palliative care in dementia: carers must be included; by Jenny Henderson.

Journal of Dementia Care, vol 15, no 2, March/April 2007, pp 22-23.

Family carers are rarely supported or encouraged to remain involved once their relative with end-stage dementia has moved into a care home. In this first of two research articles, the author makes the point that if we are to begin to meet palliative care needs, this situation must change. (RH)

ISSN: 13518372

From : Email: shital@hawkerpublications.com

Palliative care in dementia: caring at home to the end; by Jenny Henderson.

Journal of Dementia Care, vol 15, no 3, May/June 2007, pp 22-23.

In this second of two research articles, the author argues that adequate support should be given to carers who wish to care for a person with end-stage dementia at home. She writes in the light of her work for Alzheimer's Scotland palliative care project, which considered the difficulties met by carers and their support needs. (RH)

ISSN: 13518372

From : Email: shital@hawkerpublications.com

Rethinking palliative care: a social role valorisation approach; by Paul Sinclair. Bristol: The Policy Press, 2007, 246 pp.

It is argued that palliative care does not deliver on its aims to value people who are dying and to make death and dying a natural part of life. The author argues for the de-institutionalisation of palliative care and the development of an alternative framework to the approaches found in hospices, palliative care units and community-based palliative care services. He draws on Wolf Wolfenberger's social role valorisation (SRV) theory, most recently defined as "the application of what science can tell us about the enablement, establishment, enhancement, maintenance and/or defence of valued social roles for people". The book is arranged in three parts, the first of which reviews the evolution of palliative care in the context of formal care. Part Two explores the social devaluation of people who are dying as the necessary effect of how palliative care is organised; and SRV is suggested as a tool for analysing the palliative care system and for remedying social devaluation. Part Three applies ideas for tackling social devaluation in palliative care that are used in the intellectual disability services sector, particularly the shift away from institutional models of care. (RH)

Price: £21.99 (pbk); £70.00 (hbk)

From : Marston Book Services, PO Box 269, Abingdon, Oxon OX14 4YN. Email: direct.orders@marston.co.uk Website: <http://www.policypress.org.uk>

2006

Aging, spirituality and palliative care; by Elizabeth MacKinlay (ed). Binghamton, NY: The Haworth Pastoral Press, 2006, 259 pp.

This collection of papers is based on presentations made at the Third International Conference on Ageing and Spirituality. The three main aims of the conference were to: explore the growing knowledge and practice base of ageing and spirituality; bring researchers and practitioners together to examine spirituality in later life and strategies for providing best practice in aged care; and examine the latest developments in palliative care and ageing. Papers in Part I consider compassion, death and dying; also spiritual reminiscence work with people with dementia, and the spiritual needs of those who are dying including Buddhist and Christian perspectives. The last three papers (Part II) have a palliative care approach, and focus on providing appropriate care for older people who are dying. This volume has been published simultaneously as *Journal of Religion, Spirituality & Aging*, vol 18, nos 2/3, 2006. (RH)

Price: \$27.95

From : The Haworth Pastoral Press, The Haworth Press Inc., 10 Alice Street, Binghamton, NY 13904-1580, USA. <http://www.HaworthPress.com>

The assessment and implementation of mouth care in palliative care: a review; by J L Gillam, David G Gillam.

Journal of the Royal Society for the Promotion of Health, vol 126, no 1, January 2006, pp 33-37.

From a review of the literature published between 1985 and 1999, it is evident that the importance and maintenance of oral health for patients with cancer is recognised as an integral part of basic nursing care. Yet from practical observation in the hospital environment together with reviewing the published literature, it is clear there appears to be limited evidence of regular assessment of the mouth or implementation of oral protocols on the ward. Articles selected highlight the lack of published research; and their results raise concern about the lack of training and education for nurses in the assessment of mouth care, as well as the need to rationalise the assessment tools used in the ward or hospice. While it was recognised in palliative care that a multiprofessional approach was beneficial, in practice this did not appear to apply to mouth care with a few notable exceptions. This review highlights inconsistencies in both the knowledge of mouth care and its implementation by nursing staff. The importance of establishing protocols and setting standards of care was also indicated in this review. It is clear that without effective assessment of the mouth, the appropriate implementation of care will not be delivered. (RH)

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From : <http://rsh.sagepub.com>

The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review; by Jenn Burt, Rosalind Raine.

Age and Ageing, vol 35, no 5, September 2006, pp 469-476.

There is some evidence that older people are less likely to be referred to, or to use, specialist palliative care (SPC). In a systematic review, Medline, Embase, Web of Science, HMIC, SIGLE and AgeInfo were searched for studies published between 1966 and March 2005, and references in the articles identified were also examined. Inclusion criteria were all studies which provided data on age in relation to use of or referral to SPC. 14 studies were identified. All reported a statistically significant lower use of SPC among older cancer patients (age 65+) at a univariate level. However, there were important methodological weaknesses in all of the studies identified; most crucially, studies failed to consider variations in use in relation to need for SPC. (RH)

ISSN: 00020729

From : <http://www.ageing.oxfordjournals.org>

Exploring palliative care for people with dementia: a discussion document - August 2006; by National Council for Palliative Care; Alzheimer's Society. London: National Council for Palliative Care - NCPC, 2006, 23 pp.

Palliative care is defined as the active holistic care of patients with advanced, progressive illness. This document aims to raise awareness and encourage debate around issues concerning the palliative care needs of people with dementia. It outlines the policy and demographic contexts; considers the experiences of dying for people with dementia; and explores some of the specific palliative care needs of people with dementia. Of many key challenges in helping meet the palliative needs of people with dementia and their family carers, the document highlights three: assessment; education and training; and support for family carers. (RH)

ISBN: 1898915059

Price: £15

From : NCPC, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.<http://www.ncpc.org.uk>

The influence of patient and carer age in access to palliative care services; by Gunn E Grande, Morag C Farquhar, Stephen I G Barclay (et al).

Age and Ageing, vol 35, no 3, May 2006, pp 267-272.

Older patient age is associated with poorer access to palliative care. This may mask age differences in access due to a carer's age. This study compared patients who received community Macmillan nurse specialist advice, Marie Curie nursing or inpatient hospice care with patients who did not. 123 primary carers were interviewed. The study found that carer age was at least as important as patient age in predicting access to palliative home care. If carer age differences reflect that younger carers have greater need for support, health professionals may need to become more responsive to the support requirements of younger carers. If carer age differences reflect younger carers' greater effectiveness in recruiting care, there is a need to ensure that older carers' home care requirements are better heard and responded to by health professionals. (RH)

ISSN: 00020729

From : <http://www.ageing.oxfordjournals.org>

Palliative care and end-of-life care world wide web resources for geriatrics; by Ginna E Deitrick, Alyson Timlin, Bryan Gardner (et al).

Journal of Pain & Palliative Care Pharmacotherapy, vol 20, no 3, 2006, pp 47-56.

This paper reports the results of a systematic evaluation and critique of 15 United States websites. It summarizes their contribution to clinical care guidelines, teaching materials and training opportunities, effective models of care and advice on dealing with the complex emotional, social and financial issues facing older adults at the end-of-life. (KJ/RH)

ISSN: 15360288

From : Haworth Document Delivery Service, The Haworth Press Inc., 10 Alice Street, Binghamton NY 13904-1580, USA. <http://www.HaworthPress.com>

Provision of palliative care education in nursing homes; by Kathryn Mathews, Jemma Finch.

Nursing Times, vol 102, no 5, 31 January 2006, pp 36-40.

The nature and extent of existing palliative care education activities is considered. Following a literature review, the authors gathered data by questionnaires, face-to-face and telephone interviews, visiting palliative care teams across the Mount Vernon Cancer Network in Middlesex, and attendance at conferences, meetings and exhibitions. A comprehensive needs assessment for palliative care education within nursing homes was completed. The findings revealed inequalities across the network with regard to educational provision and uptake of palliative care services. Recruitment of overseas staff and a transient workforce were both cited as major difficulties in implementing educational programmes. Funding of these programmes and responsibility for providing the education remain unclear. A real and urgent need for palliative care training was found across the network area, with scope for a variety of approaches to be adopted in delivering training. (RH)

ISSN: 09547762

From : <http://www.nursingtimes.net>

A sweeter palliative: [responsive end of life care for ethnic population groups]; by Yasmin Gunaratnam.

Community Care, no 1642, 28 September 2006, pp 36-37.

As ethnic minority populations age in the UK, how can we ensure that they receive responsive end-of-life care? This article discusses findings from the Stories that Matter, a project that used narrative interviews to collect the experiences of life-limiting illness and care among ethnic minority elders, carers, and social and health care professionals. It highlights the ways in which social work can support the care choices of older people from ethnic minorities. The project was managed by the Policy Research Institute on Ageing and Ethnicity (Priae) and funded by the Department of Health (DH). (RH)

ISSN: 03075508

From : <http://www.communitycare.co.uk>

2005

A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia; by E L Sampson, C W Ritchie, R Lai (et al).

International Psychogeriatrics, vol 17, no 1, March 2005, pp 31-40.

Patients with dementia often receive poor end-of-life care with inadequate pain control and without access to palliative care services that patients with cancer are offered. This has been identified as an area of need in recent UK reports (e.g. National Service Framework for Older People, NSF, Standard Two) and by the Alzheimer's Society (UK). The authors' objective was to perform a systematic review of the scientific literature regarding the efficacy of a palliative care model for patients with dementia. Data sources included Medline, EMBASE, PsycINFO, CINAHL, British Nursing Index, AMED, Cochrane Database of Systematic Reviews, Web of Science, Cochrane Central Register of Controlled Trials, International Standard Randomised Controlled Trial register, the NHS Economic Evaluation Database, and the System for Information on Grey Literature in Europe (SIGLE). Other data was sourced from hand searches of papers identified on electronic databases and review articles. The search identified 30 review articles, but only 4 papers were eligible for full approval, and only 2 of these met full criteria for inclusion. These papers gave equivocal evidence of the efficacy for a palliative model of care in dementia. Despite the increased interest in palliative care for patients with dementia, there is currently little evidence on which to base such an approach. This may in part be due to ethical difficulties surrounding such research, prognostic uncertainty in clinicians and the lack of clear outcome measures for patients who are unable to express their needs or wishes. (RH)

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From : <http://journals.cambridge.org>

2004

Evidence-based pain management and palliative care in The Cochrane Library; by Phillip J Wiffen.

Journal of Pain & Palliative Care Pharmacotherapy, vol 18, no 1, 2004, pp 79-86.

The Cochrane Library of systematic reviews is published quarterly. Issues 2 (May 2003) and 3 (July 2003) are under discussion here. Issue 2 contained 2,395 reviews of which 1,669 are in full text; 79 are new reviews, 7 of which are directly relevant to pain management and palliative care. Annotated bibliographies for those 7 reviews are provided. Issue 3 contained 3,058 reviews and protocols, of which 1,754 are fully published reviews; 85 are new reviews, 5 of which are relevant to practitioners in pain and palliative care. References are published in the same format as the citation for Cochrane reviews. The Cochrane trials database now stands at over 375,000 records with an additional 4,100 one-page summaries of non-Cochrane reviews in the NHS database of reviews of effectiveness (DARE). (KJ/RH)

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From : Haworth Document Delivery Service, The Haworth Press Inc., 10 Alice Street, Binghamton NY 13904-1580, USA. <http://www.HaworthPress.com>

"It's different from my culture; they're very different": providing community-based, "culturally competent" palliative care for South Asian people in the UK; by Alastair Owens, Gurch Randhawa.

Health & Social Care in the Community, vol 12, no 5, September 2004, pp 414-421.

The findings are discussed of a phenomenological study of service providers' attitudes to and experiences of caring for South Asian cancer patients in Luton. 10 semi-structured in-depth interviews were carried out with a range of staff who work in home- and community-based palliative care settings, including nurses, community liaison personnel and representatives of non-statutory organisations. The authors consider how these service providers construct ideas of cultural difference, and how these relate to philosophies of palliative care. They examine attempts to deal with cultural diversity in everyday practice, focusing particularly on the social context of care in the home. The paper considers ways in which staff attempt to incorporate the cultural needs of patients, family, kin and community. Rather than criticising current working practices, the authors highlight the complexity of delivering culturally competent services from the perspective of those working directly with patients. In doing so, they contribute to ongoing debates about the development of anti-discriminatory practice in health and social care. (RH)

ISSN: 09660410

From : www.blackwellpublishing.com/hsc

2003

End-of-life care in assisted living and related residential care settings: comparison with nursing homes; by Philip D Sloane, Sheryl Zimmerman, Laura Hanson (et al).

Journal of the American Geriatrics Society, vol 51, no 11, November 2003, pp 1587-1594.

Of all deaths involving older people in the US, 21% occur in a long-term care facility. This study defined the state of end-of-life care in 55 residential care or assisted living (RC/AL) facilities and 26 nursing homes (NHs); and the two types of care settings were compared. Telephone interviews were conducted with 224 staff members and family informants who best knew 73 RC/AL residents and 72 NH residents who died within 3 days after discharge from a study facility. Data were collected on circumstances of death, perceptions of the dying process, cause of death, care during the last month of life, mood, discomfort, and family satisfaction. Most decedents had died in the facility where they had resided; more than half were alone when they died. Greater proportions of staff and family in the NHs knew that the resident's death was only days or weeks away. Both RC/AL and NH residents experienced few highly negative moods; and even on their most uncomfortable day, the overall discomfort was low for residents in both facility types. Summary ratings of family satisfaction were significantly higher for the RC/AL than the NH group. (RH)

ISSN: 00028614

The International Association for Hospice and Palliative Care: international activities and future initiatives; by Liliana De Lima, Eduardo Bruera, Roger Woodruff.

Journal of Pain & Palliative Care Pharmacotherapy, vol 17, no 1., 2003, pp 31-37.

The International Association for Hospice and Palliative Care (IAHPC) is a global organisation dedicated to the development and improvement of palliative care. Its mission is to increase the availability and access to high quality hospice and palliative care for patients and families throughout the world. It does this by promoting communication, facilitating and providing education, and by becoming an information resource for patients, professionals, health care providers and policy makers around the world. This article outlines the IAHPC's activities and planned future initiatives. (KJ/RH)

ISSN: 15360288

From : Haworth Document Delivery Service, The Haworth Press Inc., 10 Alice Street, Binghamton NY 13904-1580, USA.

2000

The level of need for palliative care: a systematic review of the literature; by Peter J Franks, Chris Salisbury, Nick Bosanquet (et al).

Palliative Medicine, vol 14, 2000, pp 93-104.

Palliative care services have developed rapidly over the last 30 years, with little evaluation as to how needs have been met by these new services. This literature view has found 64 articles providing evidence on the need for palliative care services over the period 1978 to 1997, with a further 9 more recent articles. Need can be assessed in one of two ways: either by adopting an epidemiological approach, or by examining health service usage. In the former, evidence is provided on disease-specific mortality, and related to the duration of symptoms prior to the patient's death. For the latter, estimates might be made of numbers of cases and of the specialised manpower required. Studies indicate that at present usage, palliative care is being provided by 40-50 hospice beds per million population. Despite this provision, there remains evidence that in certain areas of care such as pain control, there still remains a high degree of unmet need. (RH)

ISSN: 02692163

Palliative care needs of hospital inpatients; by Polly Edmonds, Saffron Karlsen, Julia Addington.

Palliative Medicine, vol 14, 2000, pp 227-228.

A short case-note survey by the King's College Hospital Palliative Care Team (PCT) confirms that studies assessing unmet needs of patients with advanced disease should be encouraged, in line with the development of palliative care services. (RH)

ISSN: 02692163

1996

The good and bad death perceptions of health professionals working in palliative care; by Joseph T S Low, Sheila Payne.

European Journal of Cancer Care, vol 5, 1996, pp 237-241.

Palliative care aims to cater for both psycho-social needs and alleviation of physical symptoms of dying patients. This is reflected by the good and bad death perceptions of palliative care workers, though increasing signs of institutionalisation in palliative care have challenged the idealisation of a good death. This study of health professionals' perceptions of a good death depended on controlling patients' physical symptoms and psychologically preparing them, whilst a bad death was perceived as an inability to control pain or deal with any psychological distress. Factor analysis revealed three main factors in the perception of a good death: lack of patient distress; patient control; and staff's supporting role perceptions. Four factors are identified with the perception of a bad death: the negative effects of death on the family; a patient's non-acceptance of death; not dealing with patients' fears; and the age of the dying person. Overall, health professionals perceived themselves to be open and sensitive in communicating with patients, although most respondents felt poorly supported by other staff. (RH)

1994

Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives?; by John Hinton.

Palliative Medicine, vol 8, 1994, pp 183-196.

A study of 77 cancer patients and their relatives found that 90% of their care was at home, 29% died at home, but 30% were finally admitted for one to three days, and 41% for longer. In the final eight weeks, tolerable physical symptoms were volunteered by a mean of 63% of patients each week, and psychological symptoms by 17%. Some distress was felt by 11% of patients; this was usually from pain, depression, dyspnoea, anxiety or weakness, and generally did not persist. Relatives suffered grief, strain or their own ill health. Patients' and relatives' reports generally matched, except for strain on carers. Various proportions of patients coped by optimism, fighting their disease, partial suppression or denial, but 50% reached positive acceptance. Relatives were more aware and accepting. Home treatment was usually praised; but realistic preference for home care fell steadily from 100% to 54% of patients and 45% of relatives. At follow-up, most relatives approved of where patients had received care and died. (RH)

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