

Centre for Policy on Ageing
Information Service

Selected Readings

**Palliative Care of Older
People**

November 2018

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2018

Caring about dying persons and their families: interpretation, practice and emotional labour; by Laura M Funk, Sheryl Peters, Kerstin Stieber Roger.: Wiley, July 2018, pp 519-526.

Health and Social Care in the Community, vol 26, no 4, July 2018, pp 519-526.

The importance of emotional support for dying people and their families has been well established, yet we know less about how care workers understand emotional processes related to death and dying, or how these understandings are connected to care practices and emotional labour at the end of life. The aim of this study was to explore how healthcare workers interpret and respond to emotional needs of dying people and their families. Qualitative data were collected between 2013 and 2014 through in-depth, in-person interviews with 14 nurses and 12 healthcare aides in one Western Canadian city. Transcripts were analysed using an inductive, interpretive thematic coding approach and the analytic lens of emotional labour. Dominant interpretive frames of a "good death" informed participants' emotionally supportive practice. This included guiding patients and families to "open up" about their emotions to activate the grief process. There was concern that incomplete grieving would result in anger being directed towards care staff. The goal of promoting emotional sharing informed the work of "caring about". Although palliative philosophies opened up moral and professional space for "caring about" in the context of organisational norms which often discouraged these practices, the tension between the two (and the lack of time for this work) may encourage surface expressions rather than authentic emotional care. (RH)

ISSN: 09660410

From : <http://www.wileyonlinelibrary.com/journal/hsc>

Comfort care, peace and dignity at the end of life; by Angela Liddament.: Hawker Publications, May-June 2018, pp 21-23.

Journal of Dementia Care, vol 26, no 3, May-June 2018, pp 21-23.

Good end of life care is essential in dementia, but is not always delivered. The author explains her role as an advanced nurse practitioner at Rawthorpe Care Village in Norwich. She has developed her own approach to "comfort care" (care oriented to the end of life), as something sensitive to the needs of residents with advanced dementia. Communicating an understanding of comfort care to carers and family members can also give them a chance of a bereavement that is peaceful. (RH)

ISSN: 13518372

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

Dying at home in rural residential aged care: a mixed-methods study in the Snowy Monaro region, Australia; by Suzanne Rainsford, Christine B Phillips, Nicholas J Glasgow (et al.): Wiley, September 2018, pp 705-713.

Health and Social Care in the Community, vol 26, no 5, September 2018, pp 705-713.

Residential aged care (RAC) is a significant provider of end-of-life care for people aged 65 years and older. Rural residents perceive themselves as different to their urban counterparts. Most studies describing place of death (PoD) in RAC are quantitative and reflect an urban voice. Using a mixed-methods design, this paper examined the PoD of 80 RAC residents. Of these, 15 were short-stay residents who died in RAC during respite or during an attempted step-down transition from hospital to home and 65 were permanent residents. All residents were based in the rural Snowy Monaro region of Australia and died between 1 February 2015 and 31 May 2016. Death data were collected from local funeral directors, RAC facilities, one multi-purpose health service and obituary notices in the local media. The outcome variable was PoD: RAC, local hospital or out-of-region tertiary hospital. For the permanent RAC residents, the outcome of interest was dying in RAC or dying in hospital. Cross tabulations by PoD and key demographic data were performed. Pearson Chi squared tests and exact p-values were used to determine if any of the independent variables were associated with PoD. Using an ethnographic approach, data were collected from 12 face-to-face, open-ended interviews with four RAC residents with a life expectancy of six months or less, and six family caregivers. Interviews were audio-recorded, transcribed and analysed thematically. 51 (78.5%) of the permanent residents died in RAC; 21.5% died in hospital. Home was the initial preferred PoD for most interviewed participants; most eventually accepted the transfer to RAC. Long-term residents considered RAC to be their 'home' - a familiar place, and an important part of their rural community. The participants did not consider a transfer to hospital to be necessary for end-of-life care. Further work is required to explore further the perspectives of rural RAC residents and their families, and if transfers to hospital are avoidable. (JL)

ISSN: 09660410

From : <http://www.wileyonlinelibrary.com/journal/hsc>

Moving from place to place in the last year of life: a qualitative study identifying care setting transition issues and solutions in Ontario; by Donna M Wilson, Stephen Birch.: Wiley, March 2018, pp 232-239.

Health and Social Care in the Community, vol 26, no 2, March 2018, pp 232-239.

As death nears, moving from one care setting to another is common. Many concerns exist over these end-of-life (EOL) care setting transitions, including low-quality moves as mistakes and other mishaps can occur. Delayed or denied moves are also problematic, such as a move out of hospital for dying inpatients who want to spend their last hours or days at home. This Canadian study aimed to identify current issues or problems with care setting transitions during the last year of life as well as potential or actual solutions for these problems. A grounded theory analysis approach was used based on interviews with 38 key informants representing a wide range of healthcare providers, healthcare managers, government representatives, lawyers, healthcare recipients and their family or friends across Ontario in 2016. Three interrelated themes were revealed: communication complexities; care planning and coordination gaps; and health system reform needs. Six solutions were highlighted, which were designed to prevent care setting transition issues and to monitor care setting transitions for continued improvements. (RH)

ISSN: 09660410

From : <http://wileyonlinelibrary.com/journal/hsc>

Reappraising 'the good death' for populations in the age of ageing; by Kristian Pollock, Jane Seymour.: Oxford University Press, May 2018, pp 328-330.

Age and Ageing, vol 47, no 3, May 2018, pp 328-330.

This is the second in an occasional series of paired commentaries in Age and Ageing, the Journal of the British Geriatrics Society and the Journal of the American Geriatrics Society (JAGS). The aim is to address issues of current significance, and to foster dialogue and increased understanding between academics and clinicians working in comparative international settings. Both commentaries address the urgent need to improve palliative care for older people, with a critique of some stereotypes surrounding palliative care and the 'good death'. The companion commentary, published in JAGS, was written by Alexander Smith and Vyjeyanthi Periyakoil, and is grounded in their experience as academic clinicians (Smith A K, Periyakoil V, Should we bury 'The Good Death'? Journal of the American Geriatrics Society 2018; in press). In the present paper, the authors offer a perspective on the outcome and wider consequences of misalignment between current UK policy and aspirations for end of life care in relation to epidemiological trends and patient experience of death and dying. (RH)

ISSN: 00020729

From : <https://academic.oup.com/ageing>

2017

Broadening end-of-life comfort to improve palliative care practices in long term care; by Tamara Sussman, Sharon Kaasalainen, Susan Mintzberg ... (et al.): Cambridge University Press, September 2017, pp 306-317.

Canadian Journal on Aging, vol 36, no 3, September 2017, pp 306-317.

This study aimed to (1) explore how palliative care in long-term care (LTC) addresses the tensions associated with caring for the living and dying within one care community, and (2) to inform how palliative care practices may be improved to better address the needs of all residents living and dying in LTC as well as those of the families and support staff. This article reported findings from 19 focus groups and 117 participants. Study findings revealed that LTC home staff, resident and family perspectives of end-of-life comfort applied to those who were actively dying and to their families. Findings further suggested that eliciting residents' perceptions of end-of-life comfort, sharing information about a fellow resident's death more personally, and ensuring that residents, families and staff could constructively participate in providing comfort care to dying residents could extend the purview of end-of-life comfort and support expanded integration of palliative principles within LTC. (JL)

ISSN: 07149808

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

Compassion fatigue and compassion satisfaction in hospice social work; by Sally B Pelon.: Taylor and Francis, April-September 2017, pp 134-150.

Journal of Social Work in End-of-Life and Palliative Care, vol 13, nos 2-3, April-September 2017, pp 134-150.

As part of the interprofessional team of hospice caregivers, social workers are exposed to multiple stressors, both in their work with dying patients and their families and in functioning as professionals within rapidly changing health care organisations. Ongoing exposure to such stressors prompts concern about the emotional and psychological effect working with people who are dying may have on those who do it. Furthermore an understanding is needed regarding how hospice social workers interpret the costs and benefits of their work and how they cope with the dying and loss that pervade their everyday work lives. This descriptive, cross-sectional

study explored the prevalence of compassion fatigue among hospice social workers and considered compassion satisfaction as a means to mitigate compassion fatigue. 55 hospice social workers from 34 hospice organisations in Michigan completed an online survey. Results suggested that compassion fatigue is indeed a concern among hospice social workers. In addition compassion fatigue and compassion satisfaction were found to be negatively correlated and suggested that compassion satisfaction may act as a protective mechanism against compassion fatigue. These results may provide insight regarding how best to mitigate this professional hazard in end-of-life social work. (JL)

ISSN: 15524256

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

How empowering is hospital care for older people with advanced disease?: barriers and facilitators from a cross-national ethnography in England, Ireland and the USA; by Lucy Ellen Selman, Barbara A Daveson, Melinda Smith (et al).: Oxford University Press, March 2017, pp 300-309.

Age and Ageing, vol 46, no 2, March 2017, pp 300-309.

Patient empowerment, through which patients become self-determining agents with some control over their health and healthcare, is a common theme across health policies globally. Most care for older people is in the acute setting, but there is little evidence to inform the delivery of empowering hospital care. This study aimed to explore challenges to and facilitators of empowerment among older people with advanced disease in hospital, and the impact of palliative care. The authors conducted an ethnography in six hospitals in England, Ireland and the USA. The ethnography involved: interviews with patients aged 65 and above, informal caregivers, specialist palliative care (SPC) staff and other clinicians who cared for older adults with advanced disease, and fieldwork. Data were analysed using directed thematic analysis. Findings from 91 interviews and 340 hours of observational data revealed substantial challenges to empowerment: poor communication and information provision, combined with routinised and fragmented inpatient care, restricted patients' self-efficacy, self-management, choice and decision-making. Information and knowledge were often necessary for empowerment, but not sufficient: empowerment depended on patient-centredness being enacted at an organisational and staff level. SPC facilitated empowerment by prioritising patient-centred care, tailored communication and information provision, and the support of other clinicians. Empowering older people in the acute setting requires changes throughout the health system. Facilitators of empowerment include excellent staff-patient communication, patient-centred, relational care, an organisational focus on patient experience rather than throughput, and appropriate access to SPC. Findings have relevance for many high- and middle-income countries with a growing population of older patients with advanced disease. (JL)

ISSN: 00020729

From : <https://academic.oup.com/ageing>

Palliative care in residential aged care: an overview; by Juliet Butler.: Wiley, December 2017, pp 258-261.

Australasian Journal on Ageing, vol 36, no 4, December 2017, pp 258-261.

The objective of this Australian study was to measure how care needs, health and length of stay in permanent residential aged care differ by assessed need for palliative care. On entry into permanent residential aged care, people's care needs and health conditions were assessed on the Aged Care Funding Instrument. Data for the period 2008-2009 and 2015-2016 were analysed for trends in care needs, health conditions, length of stay and separation reason across assessed need for palliative care. Study results showed that assessed care needs increased for all people in residential aged care over these periods, and people appraised for palliative care were more likely to be rated 'high' in need for support in activities of daily living. People appraised for palliative care had a higher prevalence of cancer and shorter lengths of stay. Palliative care appraisal is associated with increased complexity in assessed care needs, different profiles of health and shorter lengths of stay in permanent residential aged care. (JL)

ISSN: 14406381

From : <http://www.wileyonlinelibrary.com/journal/ajag>

Quality of care for people with dementia and professional caregivers' perspectives regarding palliative care in Japanese community care settings; by Miharū Nakanishi, Kayo Hirooka, Yuko Morimoto, Atsushi Nishida.: Wiley, December 2017, pp 1342-1351.

International Journal of Geriatric Psychiatry, vol 32, no 12, December 2017, pp 1342-1351.

Palliative care for dementia includes psychosocial interventions as first-line treatment for challenging behaviour. However the national dementia plan in Japan contradicts recommendations for palliative care for dementia. This study aimed to examine the association between care quality for patients with dementia and professional caregivers' perspectives regarding palliative care for dementia in Japanese community care settings. 2,116 professional caregivers from 329 agencies (217 in-home long-term care support providers; 29 small-scale, multiple home-care providers; and 83 group homes) in Tokyo prefecture, Japan, completed cross-sectional,

paper-based questionnaires about 3,603 people diagnosed with dementia during May 2016. Quality of care measures included physical restraint and antipsychotic medication use and quality of life. Patients' quality of life was assessed via the Japanese version of the Alzheimer's Disease Health-related Quality of Life scale. The Japanese version of the Questionnaire on Palliative Care for Advanced Dementia was used to assess professional caregivers' knowledge and attitudes regarding palliative care for dementia. Professional caregivers' knowledge and attitudes regarding palliative care for dementia were positively associated with quality of life in patients with dementia. Physical restraint and antipsychotic medication were used regardless of professional caregivers' knowledge and attitudes. Caregivers' perspectives regarding palliative care for dementia could have exerted a positive effect on quality of life in patients with dementia. A national strategy for advocacy and the protection of adults is required to integrate several laws and guidelines and prevent the use of antipsychotics as a form of chemical restraint. (JL)

ISSN: 08856230

From : <http://www.orangejournal.org>

Stepwise Psychosocial Palliative Care: a new approach to the treatment of posttraumatic stress disorder at the end of life; by David B Feldman.: Taylor and Francis, April-September 2017, pp 113-133.

Journal of Social Work in End-of-Life and Palliative Care, vol 13, nos 2-3, April-September 2017, pp 113-133.

Although evidence-based therapies for Posttraumatic Stress Disorder (PTSD) exist for physically healthy populations these do not adequately address PTSD in dying patients. Particularly because these interventions require 8-16 weekly sessions and the median stay in U.S. hospices is 17.5 days (National Hospice and Palliative Care Organization [NHPCO], 2015), there is a potentially serious timing mismatch. Moreover these treatments may temporarily increase trauma symptoms, resulting in some patients dying in greater distress than had they not received care. The Stepwise Psychosocial Palliative Care (SPPC) model presented in this article compensates for these difficulties by embracing a palliative care approach to PTSD. Although it utilises techniques drawn from existing PTSD interventions, these are re-ordered and utilised in a time-responsive, patient-centred manner that takes into account prognosis, fatigue and logistical concerns. The SPPC approach is further considered with respect to existing social work palliative care competencies (Gwyther et al., 2005) and a case study is used to demonstrate its application. (JL)

ISSN: 15524256

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

"Unexpected and distressing": understanding and improving the experience of transferring palliative care inpatients to residential care; by Voula Kallianis, Lynette Joubert, Sue Gorman (et al.): Taylor and Francis, April-September 2017, pp 193-204.

Journal of Social Work in End-of-Life and Palliative Care, vol 13, nos 2-3, April-September 2017, pp 193-204.

The increasing survival of older patients with advanced cancer is leading to a demand in palliative care, however few are able to offer long-stay admission for those whose symptoms have stabilised. When a patient no longer requires specialist palliative care services, transfer from an inpatient palliative care facility may then be necessary. A core component of the role of palliative care social workers involves working with patients and their families/carers when the care pathway shifts and the option of residential aged care facility (RACF) needs to be considered. This research explored several issues, including the impact of this transition on the patient and their families and on the interdisciplinary health care team treating the patient. An investigation was undertaken to identify concerns and barriers regarding the transition from hospice care to RACF and opportunities were highlighted to improve clinical practice in this area. Members of the interdisciplinary team were interviewed and social workers working in similar inpatient palliative care facilities undertook telephone interviews to gauge their experiences. A thematic analysis discerned a number of themes highlighting the impact of this transition on key stakeholders and incorporated recommendations to improve or best manage this process. The research has highlighted the difficulties that patients/families encounter in this transition, as well as the emphases of protecting the integrity of the patient and family. This is achieved by holding open and ongoing dialogue, working in collaboration with the patient, the family and the team. This research incorporated the voices of terminally ill patients, families, and members of the health care team in order to understand their views and recommendations for best managing the transition from a hospice/inpatient palliative care facility to a RACF. This enables their input to have some real impetus in clinical practice and service delivery. (JL)

ISSN: 15524256

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

2016

Approaches to capturing the financial cost of family care-giving within a palliative care context: a systematic review; by Clare Gardiner, Louise Brereton, Rosemary Frey, Laura Wilkinson-Meyers, Merryn Gott.: Wiley, September 2016, pp 519-531.

Health and Social Care in the Community, vol 24, no 5, September 2016, pp 519-531.

The economic burden faced by family caregivers of people at the end of life is well recognised. Financial burden has a significant impact on the provision of family care-giving in the community setting, but has seen limited research attention. A systematic review with realist review synthesis and thematic analysis was undertaken to identify literature relating to the financial costs and impact of family care-giving at the end of life. This paper reports findings relating to previously developed approaches which capture the financial costs and implications of caring for family members receiving palliative/end-of-life care. Seven electronic databases were searched from inception to April 2012, for original research studies relating to the financial impact of care-giving at the end of life. Studies were independently screened to identify those which met the study inclusion criteria, and the methodological quality of included studies was appraised using realist review criteria of relevance and rigour. A descriptive thematic approach was used to synthesise data. Twelve articles met the inclusion criteria for the review. Various approaches to capturing data on the financial costs of care-giving at the end of life were noted; however, no single tool was identified with the sole purpose of exploring these costs. The majority of approaches used structured questionnaires and were administered by personal interview, with most studies using longitudinal designs. Calculation of costs was most often based on recall by patients and family caregivers, in some studies combined with objective measures of resource use. While the studies in this review provide useful data on approaches to capturing costs of care-giving, more work is needed to develop methods which accurately and sensitively capture the financial costs of caring at the end of life. Methodological considerations include study design and method of administration, contextual and cultural relevance, and accuracy of cost estimates. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: perspectives of older people, carers and other key stakeholders; by Anna E Bone ... (et al.): Oxford University Press, November 2016, pp 863-873.

Age and Ageing, vol 45, no 6, November 2016, pp 863-873.

Understanding how best to provide palliative care for frail older people with non-malignant conditions is an international priority. The present study aimed to develop a community-based episodic model of short-term integrated palliative and supportive care (SIPS) based on the views of service users and other key stakeholders in the United Kingdom. The study carried out transparent expert consultations with health professionals, voluntary sector and carer representatives including a consensus survey. In addition, focus groups with older people and carers were used to generate recommendations for the SIPS model. Discussions focused on three key components of the model: potential benefit of SIPS, timing of delivery and processes of integrated working between specialist palliative care and generalist practitioners. Content and descriptive analysis was employed and findings were integrated across the data sources. In all, two expert consultations, a consensus survey and three focus groups were conducted. Potential benefits of SIPS included holistic assessment, opportunity for end of life discussion, symptom management and carer reassurance. Older people and carers advocated early access to SIPS, while other stakeholders proposed delivery based on complex symptom burden. A priority for integrated working was the assignment of a key worker to co-ordinate care, but the assignment criteria remained uncertain. Key stakeholders agreed that a model of SIPS for frail older people with non-malignant conditions had potential benefits within community settings, but differed in opinion on the optimal timing and indications for this service. These findings highlight the importance of consulting all key stakeholders in model development prior to feasibility evaluation. (JL)

ISSN: 00020729

From : www.ageing.oxfordjournals.org

A good death for the oldest old; by Miles D Witham, Jo Hockley.: Oxford University Press, May 2016, pp 329-331.

Age and Ageing, vol 45, no 3, May 2016, pp 329-331.

Brief article looking at ways of caring for oldest old patients at the end of life, usually aged 85 and above. A major finding of the survey was that many of these patients still die in hospital, which is unlikely to be their preferred place of death. (JL)

ISSN: 00020729

From : www.ageing.oxfordjournals.org

The mental health and mortality impact of death of a partner with dementia; by Sunil M Shah, Iain M Carey, Tess Harris ... (et al.): Wiley Blackwell, August 2016, pp 929-937.

International Journal of Geriatric Psychiatry, vol 31, no 8, August 2016, pp 929-937.

Caring for a partner with dementia and partner bereavement are independently associated with poor health. An understanding of the health effects of living with a partner dying with dementia can help optimise support. The present study looked at health in the year before and after loss of a partner with dementia compared with other bereavements. In a UK primary care database, 2,624 older individuals whose partner died with dementia during 2005-2012 were matched with 7,512 individuals experiencing bereavement where the deceased partner had no dementia recorded. Prior to bereavement, partners of the deceased with dementia were more likely to be diagnosed with depression and receive psychotropic medication than partners from bereavements without dementia. In contrast, psychotropic medication initiation two months after dementia bereavement was lower. Compared with other bereaved individuals, mortality after bereavement was lower in men experiencing a dementia bereavement but similar in women. Prior to bereavement, those who died with dementia were less likely to receive palliative care. These findings show that in the year before bereavement, partners of individuals dying with dementia experience poorer mental health than those facing bereavement from other causes, and their partner is less likely to receive palliative care. In the year after, individuals whose partner died with dementia experience some attenuation of the adverse health effects of bereavement. Services need to address the needs of carers for individuals dying with dementia and improve access to palliative care. (JL)

ISSN: 08856230

From : www.orangejournal.org

2015

Ambitions for palliative and end of life care: a national framework for local action 2015-2020; by National Palliative and End of Life Care Partnership. London: National Palliative and End of Life Care Partnership, 2015, 29 pp.

The 27 national organisations in the Partnership have identified six ambitions on how care for those nearing death should be delivered at local level. These are that: each person is seen as an individual; each person gets fair access to care; maximising comfort and wellbeing; care is coordinated; all staff are prepared to care; and each community is prepared to help. For each ambition, the report summarises what is already known, and the "building blocks" necessary to realise this ambition. (RH)

From : Website: <http://endoflifecareambitions.org.uk/>

Managing expectations: providing palliative care in aged care facilities; by Heather Lane, Jennifer Philip.: Wiley, June 2015, pp 76-81.

Australasian Journal on Ageing, vol 34, no 2, June 2015, pp 76-81.

The present study aimed to explore the views and experiences of staff from residential aged care facilities (RACFs) and community palliative care services (CPCSs) on providing palliative and end-of-life care in RACFs. Qualitative exploratory interviews and focus groups were conducted with staff working in two RACFs and two CPCSs, and, following data saturation, a thematic analysis undertaken. 15 RACF and 15 CPCS staff participated. The overarching theme was of managing expectations in the provision of care. This included low expectations of the care available in RACFs, tensions in addressing complex decision-making and concurrent administrative expectations, and differences between views of RACF and CPCS staff regarding their respective roles. Improved understanding of the needs of RACF staff will improve the care of residents and, in turn, reduce hospitalisations. (JL)

ISSN: 14406381

From : wileyonlinelibrary.com/journal/ajag

National consultation informing development of guidelines for a palliative approach for aged care in the community setting; by Kristi Holloway, Christine Toye, Ruth McConigley ... (et al.): Wiley, March 2015, pp 21-26.

Australasian Journal on Ageing, vol 34, no 1, March 2015, pp 21-26.

This study aimed to obtain perspectives from key stakeholders to inform the development of Australian national guidelines for a palliative approach to aged care in the community setting. A descriptive, exploratory qualitative design was used. Sampling was purposive. Data were collected during audiotaped, semistructured, individual and focus group interviews that addressed the need for the guidelines and aimed to identify practice areas for inclusion. Thematic analysis was undertaken. Interviews were conducted across Australia and included 172

participants. These included: health-care providers, consumers, volunteers and researchers/educators. Themes emerging from the data were: provision of a palliative approach in community care, carer support, advance care planning, physical and psychological symptom assessment and management, psychosocial support, spiritual support, issues for Aboriginal or Torres Strait Islander people, older people from diverse cultural and language groups, and clients with special needs. Findings underpinned development of new guideline documents. (JL)

ISSN: 14406381

From : wileyonlinelibrary.com/journal/ajag

Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada; by Mo Yu, Denise Guerriere, Peter C Coyte.: Wiley Blackwell, November 2015, pp 605-618.

Health and Social Care in the Community, vol 23, no 6, November 2015, pp 605-618.

In Canada, health system restructuring has led to a greater focus on home-based palliative care as an alternative to institutionalised palliative care. However, little is known about the effect of this change on end-of-life care costs and the extent to which the financial burden of care has shifted from the acute care public sector to families. This study assessed the societal costs of end-of-life care associated with two places of death (hospital and home), using a prospective cohort design in a home-based palliative care programme. Societal cost includes all costs incurred during the course of palliative care, irrespective of payer (e.g. health system, out-of-pocket, informal care-giving costs, etc.). Primary caregivers of terminal cancer patients were recruited from the Temmy Latner Centre for Palliative Care in Toronto, Canada. Demographic, service utilisation, care-giving time, health and functional status, and death data were collected by telephone interviews with primary caregivers over the course of patients' palliative trajectory. Logistic regression was conducted to model an individual's propensity for home death. Total societal costs of end-of-life care and component costs were compared between home and hospital death using propensity score stratification. Costs were presented in 2012 Canadian dollars (\$1.00CDN = \$1.00USD). The estimated total societal cost of end-of-life care was \$34,197.73 per patient over the entire palliative trajectory (4 months on average). Results showed no significant difference ($P > 0.05$) in total societal costs between home and hospital death patients. Higher hospitalisation costs for hospital death patients were replaced by higher unpaid caregiver time and outpatient service costs for home death patients. Thus, from a societal cost perspective, alternative sites of death, while not associated with a significant change in total societal cost of end-of-life care, resulted in changes in the distribution of costs borne by different stakeholders. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journals/hsc

2014

Barriers to the provision of high-quality palliative care for people with dementia in England: a qualitative study of professionals' experiences; by Nathan Davies, Laura Maio, Krish Vedavanam, Jill Manthorpe (et al): Wiley Blackwell, July 2014, pp 386-394.

Health and Social Care in the Community, vol 22, no 4, July 2014, pp 386-394.

Approaches to palliative care that were originally developed for people with cancer are now being adopted for people with dementia, as a response to many reports of poor-quality care for people with dementia at the end of life. This study explored perceived barriers to the delivery of high-quality palliative care for people with dementia using semi-structured interviews. Recordings were transcribed verbatim and analysed using thematic analysis with an inductive approach and a coding strategy. To improve the trustworthiness of the analysis, independent reading and coding of the transcripts were undertaken, followed by discussions among the four researchers to reach agreement and consensus of the themes. Two group interviews ($n = 7$ and $n = 6$), 16 individual interviews and five interviews of pairs of professionals were conducted in 2011/2012 with participants from backgrounds in palliative care, dementia services, palliative care research and policy making. Four themes were identified as barriers to providing high-quality palliative care for people with dementia: (i) ambivalence towards the systematisation of palliative care; (ii) disconnection between services; (iii) different assumptions about training needs; and (iv) negotiation of risk. Understanding these barriers to providing high-quality palliative care for people with dementia could help in the development of a dementia-specific palliative care pathway. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

A community-of-care: the integration of a palliative approach within residential aged care facilities in Australia; by Peta McVey, Heather McKenzie, Kate White.: Wiley Blackwell, March 2014, pp 197-209.

Health and Social Care in the Community, vol 22, no 2, March 2014, pp 197-209.

This study explores the extent to which a palliative approach was being used in the organisation and provision of care for older people with complex needs living in mixed-level (a combination of low- and high-level care) residential aged care facilities (RACFs) in Australia. It also explores whether evidence-based guidelines developed in 2004 were used. This paper primarily reports on the qualitative findings. Two residential aged care organisations, one in rural New South Wales and the other in Sydney, Australia, participated. Data were collected over a 9-month period from May until December 2008. Residents, family members and aged care staff were interviewed. Thematic analysis of participant interviews shows that while the various elements of a palliative approach are incorporated into the care of high-level care residents, the discourse itself is not used. The authors argue for a new conceptualisation of care for people in mixed-level care facilities: a community-of-care, in which a palliative approach is one of several components of the care provided. The findings illuminate aged care staff experiences of providing care to high-level care residents. They also provide valuable insights into high-level care residents' perceptions of their health, care provided and the way in which they foresee their care being provided in future. These findings will be important for informing clinical practice, research and policy in these settings. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis; by Helen Seow, Kevin Brazil, Jonathan Sussman (et al).

BMJ 2014;348:g3496, 6 June 2014, 10 pp.

This pooled analysis of an Ontario, Canada retrospective cohort study found that 3109 patients treated by 11 community based specialist palliative care teams had a reduced risk of being in hospital or having an emergency department visit in the last 2 weeks of life compared to 3109 patients receiving usual care. The palliative care teams studied served different geographies and varied in team composition and size, but had the same core team members and role: a core group of palliative care physicians, nurses and family physicians who provided integrated palliative care to patients in their homes. The teams role was to manage symptoms, provide education and care, coordinate services, and be available without interruption regardless of time of day. In both care groups, about 80% had cancer and 78% received end of life homecare services for the same average duration. Across all palliative care teams (970 (31.2%) of the exposed group were in hospital and 896 (28.9%) had an emergency department visit in the last two weeks of life respectively, compared with 1219 (39.3%) and 1070 (34.5%) of the unexposed group. Despite variation in team composition and geographies, community based specialist palliative care teams were effective in reducing acute care use and hospital deaths at the end of life. (OFFPRINT) (RH)

From : <http://www.bmj.com/content/348/bmj.g3496>

2013

Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong; by Andy Hau Yan Ho, Cecilia Lai Wan Chan, Pamela Pui Yu Leung ... (et al).: Oxford University Press, July 2013, pp 455-461.

Age and Ageing, vol 42, no 4, July 2013, pp 455-461.

The empirical Dignity Model has profoundly influenced the provision of palliative care for older terminally ill patients in the West as it provides practical guidance and intervention strategies for promoting dignity and reducing distress at the end of life. The present study aimed to examine the concept of living and dying with dignity in the Chinese context, and to explore the application of the Dignity Model to older terminal patients in Hong Kong. Using qualitative interviews, the concept of dignity was explored among 16 older Chinese palliative care patients with terminal cancer. Framework analysis with both deductive and inductive methods was employed. Results showed that the three major categories of themes of the Dignity Model were broadly supported. However the subtheme of death anxiety was not supported, while two subthemes of generativity/legacy and resilience/fighting spirit manifested differently in the Chinese context. Furthermore four new emergent themes have been identified. They include enduring pain, moral transcendence, spiritual surrender and transgenerational unity. These findings highlight both a cultural and a familial dimension in the construct of dignity, underline the paramount importance of cultural awareness and competence for working with ethnically diverse groups, and call for a culturally sensitive and family oriented approach to palliative care interventions with older Chinese terminal patients. (JL).

ISSN: 00020729

From : www.ageing.oxfordjournals.org

Palliative and end of life care for Black, Asian and minority ethnic groups in the UK: demographic profile and the current state of palliative and end of life care provision; by Natalia Calanzani, Jonathan Koffman, Irene J Higginson, Cicely Saunders Institute, King's College London. London: Marie Curie Cancer Care; Public Health England; King's College London, June 2013, 77 pp.

The End of Life Care Strategy highlights that inequalities still exist in the care that different groups of people receive at the end of life. This report uses data from the 2001 and 2011 Censuses to look at the current and projected profile of Black, Asian and Minority Ethnic (BAME) populations living in the UK by ethnicity, religion, language and characteristics of the foreign born population. Figures are provided separately for England, Wales, Scotland and Northern Ireland. The report examines the extent to which the BAME populations are expected to increase and grow older in the next few decades according to the most recent population projections. The report then draws on a review of the current literature on the state of palliative and end of life care provision for BAME groups. The focus is on access to, and receipt of care; also a recognition of the importance of social inequalities when analysing unmet needs. The report was commissioned by Marie Curie Cancer Care and Public Health England to provide evidence for key stakeholders and policy makers planning future care for BAME groups, and it makes recommendations accordingly. (RH)

From : https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame_full-report.pdf

What are the priorities for developing culturally appropriate palliative and end-of-life care for older people?: the views of healthcare staff working in New Zealand; by Gary Bellamy, Merryn Gott.: Wiley, January 2013, pp 26-34.

Health and Social Care in the Community, vol 21, no 1, January 2013, pp 26-34.

In New Zealand, the ageing population is culturally and ethnically diverse; and, along with other developing countries experiencing high levels of migration, the challenge is how to balance the rise in numbers of older people from different ethnic and cultural groups with end-of-life care that reflects personal values and beliefs. This study investigated the views of healthcare staff regarding the provision of culturally appropriate palliative care for Maori, Pacific Island and Chinese elders living in Auckland, New Zealand. Two joint interviews and ten focus groups were conducted with eighty staff across a range of care settings in 2010. Findings indicate that participants viewed the involvement of family as fundamental to the provision of palliative care for Maori, Pacific Island and Chinese elders. For Maori and Pacific Islanders, healthcare staff indicated the importance of enabling family members to provide 'hands-on' care. The role of family in decision-making was fundamental to the delivery of, and satisfaction with care for older Chinese family members. Care staff highlighted the need to be cognisant of individual preferences both within and across cultures as a fundamental aspect of palliative care provision. While assumptions are sometimes made about preferences for end-of-life care based on cultural values alone, the results suggest that care preferences need to be ascertained by working with family members on an individual basis and in a manner that respects their involvement in palliative care provision. (RH)

ISSN: 09660410

From : www.wileyonlinelibrary.com/journals/hsc

2011

Barriers to providing palliative care for older people in acute hospitals; by Clare Gardiner, Mark Cobb, Merryn Gott, Christine Ingleton.

Age and Ageing, vol 40, no 2, March 2011, pp 233-242.

The study aimed to explore the perspectives of health professionals regarding barriers to optimal palliative care for older people in acute hospitals. 58 health professionals participated in eight focus groups and four semi-structured interviews. Participants identified various barriers to palliative care provision for older people, including attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources. Participants also reported differing understandings of whose responsibility it was to provide palliative care for older people, and uncertainty over the roles of specialist and generalist palliative care providers in acute hospitals. Concludes that additional research is required to further explore age-related issues contributing to poor access to palliative care. (JL)

ISSN: 00020729

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

'Doubly deprived': a post-death qualitative study of primary carers of people who died in Western Australia; by Sharon Keesing, Lorna Rosenwax, Beverley McNamara.

Health and Social Care in the Community, vol 19, no 6, November 2011, pp 636-644.

This study explored the daily experiences and occupational needs of family carers providing palliative care to people who were dying. In particular it examined their daily routines and ability to undertake other varied activities, and whether their needs were addressed in the community using available services. A purposive sampling method was used to identify ten people who had cared for a family member who had died in the preceding two years. Semi-structured interviews included questions about their experiences as a carer including routines, engagement in usual activities and the impact of the caring role on their daily life during and after the period of care. Two important themes were identified: the carers experienced disengagement and deprivation from their usual occupations during and after the period of care. They also described significant disempowerment in their role as carer. The findings show that carers are 'doubly disadvantaged': they are unable to participate in their usual occupations, and they are not recognised for their contributions as carers. In addition, the current services and support available for carers in the community are deemed inadequate. (JL)

ISSN: 09660410

From : <http://www.ingentaconnect.com/content/bsc/hssc>

Dying out-of-hours: 24/7 care at the end of life: conference report: a joint conference hosted by the National Council for Palliative Care and Macmillan Cancer Support, 3 march 2011; by National Council for Palliative Care - NCP; Macmillan Cancer Support. London: National Council for Palliative Care, 2011, 12 pp.

There is wide acceptance that high-quality care can make a large difference for patients nearing the end of life, and to their families, carers and friends. Round the clock care (now referred to as 24/7) was recognised in the 2008 End of Life Care Strategy for England as a cornerstone of palliative and end-of-life care best practice. This report summarises the main points from the 'Dying out-of-hours: 24/7 care at the end of life' conference, including examples of good practice. (RH)

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

End-of-life care in elderly cancer patients; by Sophie Pautex, Gilbert B Zulian.

Aging Health, vol 7, no 3, June 2011, pp 469-475.

In spite of increased life expectancy at the dawn of the 21st century, chronic disorders in older people are still taking their toll, with cancers being the most prevalent. The question of how to approach the end of life remains largely unresolved, however the development of palliative care may provide some answers. Although the deficits in providing good palliative care are well known in many areas, dramatic improvements have been made to allow healthcare professionals to achieve impeccable symptom control, through sedation, chemotherapy and other means. However, patients' existential suffering remains, and many are likely to become cognitively impaired. The use of advance directives may be appropriate in order to ensure patients' autonomy as they become incapable of making their own decisions. However the practice of assisted suicide and euthanasia (which are considered acceptable in some countries) are of great professional and ethical concern. Education, training and research are key elements for the development of palliative care and for the general improvement of care delivered to older patients approaching the end of their lives. (JL)

ISSN: 1745509X

From : <http://www.futuremedicine.com/loi/ahe>

Palliative and end-of-life care in psychogeriatric patients; by Abhilash K Desai, George T Grossberg.

Aging Health, vol 7, no 3, June 2011, pp 395-408.

An increasing number of older adults and their families are burdened by one or more terminal illnesses in the later years of their lives. How best to support their quality of life is a major challenge for healthcare teams. Palliative and end-of-life (PEOL) care is well positioned to respond to this challenge. While the evidence of PEOL is just beginning, much of the suffering can be relieved by what is already known. PEOL care for older adults needs to go beyond the focus on the patient and should rest on a broad understanding of the nature of suffering that includes family and professional caregivers. The dissemination of PEOL care principles should be a public health priority. This article aims to improve understanding of appropriate PEOL care and discuss future perspectives. (JL)

ISSN: 1745509X

From : <http://www.futuremedicine.com/loi/ahe>

2010

Can you see me?: an Amanda Waring film for the National Council for Palliative Care: [DVD]; by Amanda Waring, National Council for Palliative Care - NCCPC. London: National Council for Palliative Care, 2010, 1 DVD + leaflet.

This film aims to inspire and encourage providers and commissioners of end of life care to consider everyone in their community, particularly those who are often invisible, including those who are homeless, from black minority ethnic communities, and who have conditions other than cancer. It describes end of life care needs, how to respond, and ways to ask people what they want. The film could be used in training, for discussion around questions such as: Who is in your community? Are you meeting their needs? Have you asked them what they want? The leaflet also refers to Dying Matters, a national coalition led by the National Council for Palliative Care, which aims to ask such questions and to change public knowledge, attitudes and behaviours towards death, dying and bereavement (see www.dyingmatters.org). (RH)

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

National survey of patient activity data for specialist palliative care services: MDS full report for the year 2008-2009; by National Council for Palliative Care - NCCPC. London: National Council for Palliative Care, May 2010, 75 pp.

The Minimum Data Set (MDS) was developed in 1995 by the National Council for Hospice and Specialist Palliative Care Services (now the NCCPC) in association with the Hospice Service at St Christopher's Hospice, London. The aim of the MDS is to provide good quality, comprehensive data about hospice and specialist palliative care services, in order to inform service management, development, commissioning and planning. This report provides a national overview of services in England, Northern Ireland and Wales; data on inpatients and outpatients, including their ethnicity as well as diagnoses; and data on day care, community services, hospital support, and bereavement support. The data are variously presented as tables or charts, accompanied by annotations. The findings are based on an overall response rate of 66% (328 services) to a questionnaire sent to all services providing palliative care in England, Northern Ireland and Wales. (RH)

Price: £25.00 (free to NCCPC subscribers)

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

Palliative care beyond cancer; by Tony Delamothe, Mike Knapton, Eve Richardson (et al).

British Medical Journal, vol [341](#), no 7774, 25 September 2010, pp 645-662 (Spotlight).

A series of six brief reviews especially commissioned for the inaugural BMJ Spotlight series. It focuses on palliative care for non-cancer conditions and the role that it should play in modern medical care of the hospital patient or care home resident. It highlights the work being undertaken by the Dying Matters coalition; the current document published this year, of the UK's General Medical Council, "Treatment and Care towards the End of Life"; and initiatives that will raise the awareness of death and dying well in our modern society. (KJ/RH)

ISSN: 09598138

From : www.bmj.com/podcasts

The palliative care needs of acute stroke patients : a prospective study of hospital admissions; by Christopher R Burton, Sheila Payne, Julia Addington-Hall (et al).

Age and Ageing, vol [39](#), no 5, September 2010, pp 554-558.

Despite a mortality rate of approximately 30% in acute stroke, little is known about the palliative care needs of this group of patients. Prospective study of 191 acute stroke patients admitted to hospital in England. Biographical, medical and stroke-related data were collected. Participants completed the Sheffield Profile for Assessment and Referral to Care (SPARC), a screening tool for referral to specialist palliative care. Findings: over 50% reported moderate to significant fatigue-related problems. Approximately 50% reported symptom-related problems (e.g. pain) or psychological distress (e.g. anxiety). Approximately 25% had concerns about death or dying, and 66% had concerns about dependence and disability. Over 50% were worried about the impact of stroke on family members. There were significant main effects of dependence (Barthel Index) ($F_{1,123} = 12.640$ $P = 0.001$) and age ($F_{4,123} = 3.022$ $P = 0.020$), and a significant three-factor interaction between dependence, age and co-morbidities ($F_{9,123} = 2.199$ $P = 0.026$) in predicting total SPARC scores. Acute stroke patients have a high prevalence of palliative care needs. Acute stroke services should use the SPARC for needs assessment. Priority for assessment should be given to patients with a score of <15/20 on the Barthel Index, a tool already used in most stroke services. (KJ)

ISSN: 00020729

From : <http://www.ageing.oxfordjournals.org><http://www.bgs.org.uk>doi: 10.1093/ageing/afq077

A protocol for determining differences in consistency and depth of palliative care service provision across community sites; by Nadine Schuurman, Valerie A Crooks, Ofer Amram.

Health and Social Care in the Community, vol 18, no 5, September 2010, pp 537-548.

Numerous accounts document the difficulty in obtaining accurate data regarding the extent and composition of palliative care services. Compounding the problem is the lack of standardisation regarding categorisation and reporting across jurisdictions. In this study, the authors gathered both quantitative and spatial (or geographical) data to develop a composite picture that captures the extent, composition and depth of palliative care in the Canadian province of British Columbia (BC). The province is intensely urban in the southwest, and is rural or remote in most of the remainder. They conducted a detailed telephone survey of all palliative care home care teams and facilities hosting designated beds in BC. They used geographic information systems to geocode locations of all hospice and hospital facilities. In-home care data was obtained individually from each of five BC regional health authorities. In addition, they purchased accurate road travel time data to determine service areas around palliative facilities and to determine populations outside a 1-hour travel time to a facility. With this data, they were able to calculate three critical metrics: (i) the population served within 1 hour of palliative care facilities - and more critically those not served; (ii) a matrix that determines access to in-home palliative care measured by both diversity of professionals as well as population served per palliative team member; and (iii) a ranking of palliative care services across the province based on physical accessibility as well as the extent of in-home care. In combination, these metrics provide the basis for identifying areas of vulnerability with respect to not meeting potential palliative care need. In addition, the ranking provides a basis for rural/urban comparisons. Finally, the protocol introduced can be used in other areas and provides a means of comparing palliative care service provision amongst multiple jurisdictions. (KJ/RH)

ISSN: 09660410

From : <http://www.ingentaconnect.com/content/bsc/hsc>DOI: 10.1111/j.1365-2524.2010.00933.x

Specialist palliative care workforce survey 2008/2009: national summary; by Emily Sam, National Council for Palliative Care- NCPC; NHS Information Centre; NHS Workforce Review Team. London: National Council for Palliative Care, 2010, 10 pp.

The End of Life Care Strategy for England (2008) identified workforce development as one of the essential factors to the future success of the Strategy's implementation. The Strategy recognised the importance of the role of the specialist palliative care workforce. The National Council for Palliative Care (PCPC) carried out this survey in partnership with the NHS Information Centre and the NHS Workforce Review Team; the results of previous surveys carried out in 2005 and 2007 are on NCPC's website (www.ncpc.org.uk). The survey is the only comprehensive survey of the specialist palliative care workforce makeup, including both NHS and voluntary sector. This briefing gives an overview of the national results and identifies some priorities for the future; of particular concern are vacancy rates and the rising proportion of nurses who are aged over 50 (33.6% in 2008). The results of previous surveys carried out in 2005 and 2007, also reports from Strategic Health Authorities (SHAs) and cancer network levels are available free on NCPC's website (www.ncpc.org.uk). (RH)

ISBN: 1898915784

Price: £7.00 (free to NCPC 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

2009

Benchmarking analysis: needs resourcing, outputs and outcomes of palliative and end of life care; by Peter Tebbit, National Council for Palliative Care - NCPC. 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 (NCPC) 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 NCPC 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 NCOC 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 and end-of-life care in correctional settings; by John F Linder, Frederick J Meyers. Binghamton, NY: Haworth Social Work Practice Press, 2009, pp 7-33.

Journal of Social Work in End-of-life & Palliative Care, vol 5, nos 1-2, 2009, pp 7-33.

The prison population in the United States has grown fivefold in the last 27 years. Like the general population, the inmate population is ageing. With age comes infirmity, disability, and chronic conditions that may, over the course of years or decades, lead to death. Inmates enter the prison system in poorer health than their age-matched free counterparts. A growing number of inmates will die in prison. A few will receive medical or compassionate release in order to die "outside the walls." Whether inside or outside, these dying men and women are entitled to receive high quality health care, including palliative care. Dying inmates face many of the same issues as the terminally ill in free society. However, death behind bars also poses some unique challenges to the dying, their prison family, their biological family, their caregivers and health care providers, custody staff, prison administration, and society as a whole. Social workers can play an important role in the care of these individuals and the people they are connected to both in prison and beyond its confines. This article provides important background for understanding the unique and the ubiquitous aspects of dying inmates. It offers direction to social work professionals in serving these inmates, their loved ones, their custodians, and the larger society. (KJ/RH)

ISSN: 15524256

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

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 : <http://www.tandfonline.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.org.uk>

Transforming research into action: a European Parliament report on palliative care; by Jose M Martin-Moreno, Meggan Harris, Lydia Gorgojo (et al).: European Observatory on Health Systems and Policies, 2009, pp 23-25. 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 : <http://www.tandfonline.com>

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 (1071 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 is 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 Siggie 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)

ISSN: 14664240

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)

ISSN: 10416102

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)

ISSN: 15360288

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)

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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)

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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 review 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)

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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)

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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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