

Centre for Policy on Ageing
Information Service

Selected Readings

End-of-Life Care

February 2023

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2022

Dispensing care?: The dosette box and the status of low-fi technologies within older people's end-of-life caregiving practices; by Tessa Morgan, Robbie Duschinsky, Stephen Barclay. *Sociology of Health & Illness*, Vol 44, Nos 4-5, April/May 2022, pp 745-763.

Technology has been lauded as a solution to challenges presented by the ageing population internationally. While the lion's share of scholarship has focused on high-fi, digital technologies, there has been a recent shift to exploring the contributions that mundane, low-fi technologies make to older people's daily lives and our understandings of health, illness and care more broadly. Drawing from serial narrative interview data collected with 19 married couples aged 70 and over living in the UK, this article explores the way one medical technology - the dosette box - was taken-up and deployed in their end-of-life caring process. Informed by actor-network theory and critical feminist scholarship, this article considers how the dosette box played an active role in structuring relationships, scheduling daily care activities and enforcing medical compliance. In doing so, the authors suggest that the dosette box provides an unexpected companion and 'weapon of the weak' for older partners who attempt to assert their expertise and power while caring. This article also explores how, once introduced into the home, the dosette box has demanded an even higher level of regular, vital care from older partners, thus entrenching the physical and emotional demands of dispensing care. (OFFPRINT.) (RH)

ISSN: 01419889

From : <https://doi.org/10.1111/1467-9566.13455>

End-of-life care for older people: the way forward; by Nele Julienne Van Den Noortgate, Lieve Van den Block.: Oxford University Press, July 2022, pp 1-5.

Age and Ageing, vol 51, no 7, afac078, July 2022, pp 1-5.

Even though many older people will live longer in good health, many will also be confronted with frailty, multi-morbidity, cognitive decline, disability and serious illnesses in the last years of their life. The end-of-life trajectories of frail older people have a major impact on the care that needs to be provided. Older people develop different physical, psychological and/or social needs in varying intensity during the last years of life. Moreover, determining a clear terminal phase of life is difficult in this population. In this commentary, the authors aim to highlight the importance of an integrated palliative, geriatric and rehabilitative care approach for older people, emphasizing the importance of setting-specific and cross-setting interventions. They stress the importance of person-centred care planning with the older patient and the role of their families, communities and society as a whole. They identify and formulate some of the research gaps that can be addressed in the near future. Thus, a model integrating principles of palliative, geriatric, and rehabilitative medicine and care is needed, in which family, close friends, neighbours, the larger community, social and voluntary networks will play an important role. (RH)

ISSN: 14682834

From : <https://academic.oup.com/ageing/article/51/7/afac078/6637441>

Identifying shelter and housing models for older people experiencing homelessness; by Sarah L Canham, Christine A Walsh, Tamara Sussman (et al): Taylor and Francis, April-June 2022, pp 204-225.

Journal of Aging and Environment, vol 36, no 2, April-June 2022, pp 204-225.

Limited research has identified the types of shelter and/or housing and supports for the growing population of older people experiencing homelessness (OPEH) and the extent to which existing models align with their needs. To redress this gap, the authors conducted an environmental scan and three World Café workshops to identify and characterise shelter and/or housing models for OPEH in Montreal, Calgary and Vancouver (Canada). Fifty-two models were identified and categorised into six shelter and/or housing types based on the programme length of stay and level of health and social supports provided onsite: (1) Emergency, transitional or temporary shelter and/or housing with supports; (2) Independent housing with offsite community-based supports; (3) Supported independent housing with onsite, non-medical supports; (4) Permanent supportive housing with onsite medical support and/or specialised services; (5) Long-term care for individuals with complex health needs; and (6) Palliative care and/or hospice, offering end-of-life services. Models that met the unique needs of OPEH had coordinated supports, social and recreational programming, assistance with daily tasks, and had a person-centred, harm-reduction approach to care. This typology of shelter and housing models offers a basis from which local and regional governments can audit their existing shelter and/or housing options and determine where there may be gaps in supporting OPEH. (RH)

ISSN: 26892618

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

Standardising care of the dying: an ethnographic analysis of the Liverpool Care Pathway in England and the Netherlands; by Erica Borgstrom, Natashe Lemos Dekker.: Wiley, November 2022, pp 1445-1460.

Sociology of Health and Illness, vol 44, no 9, November 2022, pp 1445-1460.

The Liverpool Care Pathway for the Dying Patient (LCP) was a prominent set of guidance in the late 2000s and early 2010s within palliative and end-of-life care. Developed in England to improve the care of dying patients, it was later adopted in 20 counties. After a public scandal, it was removed from practice in England but remains in other locations, including the Netherlands. Drawing on two sets of ethnographic data, from England and the Netherlands, the authors consider the ways in which the LCP was engaged with as a form of standardisation aimed at improving practice, how it was deployed in relation to other forms of knowledge, and the political and moral statements that are being made through the (selective) use of it. Looking into the use of the LCP shows that, while the LCP attempts to standardise some of the values associated with palliative care, there are significant differences between how these standardised values are then enacted in different institutional and national contexts and by different individual care professionals. The authors conclude that the LCP was used to impart moral values, establish protocols of care, and demonstrate professionalism, showing the multiplicity of the use of standards in healthcare practice. (RH)

ISSN: 14679566

From : <https://onlinelibrary.wiley.com/journal/14679566>

2021

Adding ritualized chanting to the palliative care of cancer patients at the end of life: a randomized controlled trial; by Nopbhornphetchara Maungtoug, Pranom Othaganont, Patricia Liehr.: Taylor and Francis, 2021, pp 35-49.

Journal of Social Work in End-of-Life and Palliative Care, vol 17, no 1, 2021, pp 35-49.

This study examined the changes in comfort when adding ritualised chanting to the palliative care of cancer patients at the end of life. The method was a randomised control trial (RCT) performed with 60 cancer patients in Thailand. Comfort was measured using the End of Life Planning Questionnaire (EOLPQ) with 30 participants in each group [ritualised chanting with palliative care (RCPC) and palliative care alone (PCA)] at baseline (T1), at a 3-week (T2) and the 6-week (T3) time frame. Comfort data were analysed using two (groups) X three (time) repeated measures MANOVA. There were no significant statistical differences between the groups at baseline. Between-group differences indicated that comfort experienced by participants with the addition of ritualised chanting to palliative care significantly increased ($p < .001$) over time. The addition of ritualised chanting to the palliative care for cancer patients at the end of life can create changes in their comfort. (RH)

ISSN: 15524256

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

Case study method to design and evaluate person-centred integrated palliative and end-of-life care; by Giovanna I Cruz, Sarah M McGhee.: Emerald, 2021, pp 231-241.

Journal of Integrated Care, vol 29, no 3, 2021, pp 231-241.

This case study aims to understand the experience of care from a patient/carer perspective and to describe how the method can be replicated to address gaps in evidence relating to integrated person-centred care. The case study was constructed using data extracted from personal diaries and medical records kept by a person with a complex condition, correspondence with family from the last 18 months of life and interviews with the carer and long-term conditions coordinator. The number of professionals or teams involved in providing care from statutory services, the third sector, and private providers were counted to understand the ecosystem of care. The number of contacts was plotted by provider and purpose of care. The type of care and hours of respite were estimated. A protocol was developed to assess the feasibility of replicating the data and analyses used. There were 35 care providers from the public, private and the third sector, demonstrating that only the patient or carer can identify the ecosystem of care. The majority of care was for respite and on average, the carer provided four hours of care per every respite care hour. The method was replicated successfully. The case study formed the basis of a workshop that brought together health care professionals from the public services and the third sector. The discussion led to the identification of gaps and areas where greater coordination between providers would benefit patients.

ISSN: 14769018

From : <https://doi.org/10.1108/JICA-04-2020-0021>

Comfort care homes: pressures and protocols in end-of-life care during the COVID-19 pandemic; by Carol S Weisse, Kelly Melekis.: Taylor and Francis, 2021, pp 173-185.

Journal of Social Work in End-of-Life and Palliative Care, vol 17, nos 2-3, 2021, pp 173-185.

Comfort care homes are community-run, residential homes that provide end-of-life care to terminally ill individuals who lack safe, secure housing and a reliable caregiver system. As non-profit, non-medical facilities, these homes have faced both new and magnified challenges due to the COVID-19 pandemic. This article highlights the value of collaborative interagency partnerships, and shares reflections on the unique pandemic pressures faced by comfort care homes in New York. Innovative ideas for improving community-based end-of-life care and implications for social work practice are included. (RH)

ISSN: 15524256

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

COVID-19 2021: Special issue; by Ellen L Csikai (ed.): Taylor and Francis, 2021, pp 83-237.

Journal of Social Work in End-of-Life and Palliative Care, vol 17, nos 2-3, 2021, pp 83-237.

The underlying message from articles in this special issues of Journal of Social Work in End-of-Life and Palliative Care is that social workers responded to meet the many challenges that arose during the COVID-19 pandemic. The articles are arranged into two sections, the first being reflections, which represent thoughts, emotions and collective actions representing the work that was done during the early months of the pandemic. In the second section, on practice concepts and innovations, social workers explain how they have worked out new ways to connect with patients and families and with each other. Many of these new techniques and practices will remain. (RH)

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

Positive aspects of family caregiving for older adults at end-of-life: a qualitative examination; by Cynthia A Hovland, Christopher A Mallett.: Taylor and Francis, 2021, pp 64-82.

Journal of Social Work in End-of-Life and Palliative Care, vol 17, no 1, 2021, pp 64-82.

Family caregivers of older adults with dementia have significant challenges across many domains. While this role has been found to be burdensome on the caregiver, increasingly, though, there are also significant positive aspects reported by caregivers (known as the positive aspects of caregiving ? PAC). This participatory qualitative study of 30 United States caregivers of family members age 65 and older who died with a dementia-related diagnoses used in-depth qualitative interviews and directed content analysis to understand the data. The study addressed a gap in the research literature and asked about caregiver?s positive experiences during their family members? last weeks of life and investigated what this meant for the caregiver. Three primary themes were identified: (1) The Importance and Impact of Family Traditions and/or Celebrations, (2) Use of Humour in Living and the Difficult Experiences at End-of-Life, and (3) ?The Gift of Caregiving?. These findings are explored and reviewed in light of other research looking at the positive aspects of caregiving for caregivers taking care of people living with dementia, finding concurrence and some uniqueness across the results. Implications of the findings for families and social work professionals are reviewed. (RH)

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

Why are dying individuals stigmatized and socially avoided?: Psychological explanations; by Youngjin Kang.: Taylor and Francis, 2021, pp 317-348.

Journal of Social Work in End-of-Life and Palliative Care, vol 17, no 4, 2021, pp 317-348.

Extant research on the topic of death and dying in modern society frequently includes the observation that death is now rendered invisible, and dying individuals are stigmatised and socially avoided. The current research speculated that lack of contact with a dying individual may promote negative perceptions of the dying, and this may in turn lead to further avoidance of them. Three studies were conducted. The first study examined how frequently the current U.S. participants had social contact with a dying individual. The second study investigated what perceptions they have of the dying. The third study tested for potential causal links between negative perceptions of the dying and social avoidance of them. The results indicated that only a small number of the U.S. participants ever had frequent social contact with a dying person outside their family. Nevertheless, they shared several common negative perceptions of the dying; and those negative perceptions exerted different effects on one?s avoidant attitude toward a dying individual only, making males more avoidant, especially in a physically close social relationship. Two concepts, medicalisation and masculinism, were suggested as possible explanations as to why dying individuals are stigmatised and avoided in modern society. (RH)

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

2020

Direct and indirect predictors of burden among Bedouin caregivers of family members with terminal cancer in Israel; by Y G Bachner, M Morad, C Sroussi, N O'Rourke.: Taylor and Francis, April 2020, pp 575-581.

Aging and Mental Health, vol 24, no 4, April 2020, pp 575-581.

The diverse demands of cancer care, which require time, psychological, physical and material resources, often lead to caregiver burden. Studies with caregivers from ethnic minority groups suggest that they have unique beliefs and may experience different perceptions of role demands and caregiving. The aim of this study was to identify direct and indirect predictors of burden among Bedouin caregivers of family members with terminal cancer in Israel. 101 Bedouin family caregivers of terminal cancer patients participated in the study. Participants were recruited from the oncology department of the largest medical centre in southern Israel. The questionnaire battery included the Arabic version of the Zarit Burden Interview and other reliable measures validated for cancer caregiving. The study performed path analyses on data in order to identify hypothesised and un-hypothesised predictors of burden in this understudied population. Most caregivers were adult children, followed by spouses, siblings and other family members. In the model, caregiver burden was directly predicted by depressive symptoms and (absence of) social support. Burden was indirectly predicted by quality of life (via depressive symptoms), optimism (via social support), emotional exhaustion (via quality of life and depressive symptoms) and mortality communication (via emotional exhaustion, quality of life and depressive symptoms). Social support and depression are the most important factors among all studied measures. Culturally-tailored intervention programs are required to foster community care and mitigate burden for Bedouin and other ethnic minority groups in Israel. (JL)

ISSN: 13607863

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

Dying online: an analysis of end-of-life narratives; by Allison Gibson, Abigail L Latimer, Danielle R Silberman, Donna L Schuman.: Taylor and Francis, 2020, pp 57-76.

Journal of Social Work in End-of-Life and Palliative Care, vol 16, no 1, 2020, pp 57-76.

Technology is changing many aspects of our daily lives, including how we share our experiences. While there have been many advances in technology to sustain life, it has also led to changes in how we die. This study used publicly available online narratives (vlog postings) written by individuals diagnosed with a terminal illness, to explore themes on what dying individuals wished to say about their experiences (n = 39). While the content of the messages varied, all of the postings provided advice for living a good life. The implications of these narratives are still unknown. Questions remain about the role online peer support plays in the dying process and the extent to which sharing one's digital story can affect others online. The act of being introspective at the end of life and the desire for social connection is similar to other forms of social work intervention such as dignity therapy, suggesting an opportunity for further exploration. Additionally, these end-of-life narratives could also serve as a tool for educating future social work professionals about the experiences of those diagnosed with a terminal illness. (RH)

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

Empowering better end-of-life dementia care (EMBED-Care): a mixed methods protocol to achieve integrated person-centred care across settings; by Elizabeth L Sampson (et al.): Wiley, August 2020, pp 820-832.

International Journal of Geriatric Psychiatry, vol 35, no 8, August 2020, pp 820-832.

Globally, the number of people with dementia who have palliative care needs will increase fourfold over the next 40 years. The Empowering Better End-of-Life Dementia Care (EMBED-Care) Programme aims to deliver a step change in care through a large sequential study, spanning multiple work streams. The study will use mixed methods across settings where people with dementia live and die: their own homes, care homes, and hospitals. Beginning with policy syntheses and reviews of interventions, it will develop a conceptual framework and underpinning theory of change. The study will use linked data sets to explore current service use, care transitions, and inequalities and predict future need for end-of-life dementia care. Longitudinal cohort studies of people with dementia (including young onset and prion dementias) and their carers will describe care transitions, quality of life, symptoms, formal and informal care provision, and costs. Data will be synthesised, underpinned by the Knowledge-to-Action Implementation Framework, to design a novel complex intervention to support assessment, decision making, and communication between patients, carers, and inter-professional teams. This will be feasibility and pilot tested in UK settings. Patient and public involvement and engagement, innovative work with artists, policymakers, and third sector organisations are embedded to drive impact. The study will build research capacity and develop an international network for excellence in dementia palliative care. EMBED-Care aims to help understand current and future needs, develop novel cost-effective care

innovations, build research capacity, and promote international collaborations in research and practice to ensure people live and die well with dementia.

ISSN: 08856230

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

Factors associated with overall satisfaction with care at the end-of-life: caregiver voices in New Zealand; by Rosemary Frey (et al.): Wiley, November 2020, pp 2320-2330.

Health and Social Care in the Community, vol 28, no 6, November 2020, pp 2320-2330.

In New Zealand, as in other industrialised societies, an ageing population has led to an increased need for palliative care services. A cross-sectional postal survey of bereaved carers was conducted in order to describe both bereaved carer experience of existing services in the last 3 months of life, and to identify factors associated with overall satisfaction with care. A self-complete questionnaire, using a modified version of the Views of Informal Carers - Evaluation of Services (VOICES) instrument was sent to 4,778 bereaved carers for registered deceased adult (>18yrs) patients in one district health board (DHB) for the period between November 2015 and December 2016. Eight hundred and twenty-six completed questionnaires were returned (response rate = 21%). The majority of respondents (83.8%) rated their overall satisfaction with care (taking all care during the last 3 months into account), as high. However, satisfaction varied by care setting. Overall satisfaction with care in hospice was significantly higher compared to other settings. Additionally, patients who died in hospice were more likely to be diagnosed with cancer and under 65 years of age. The factors associated with overall satisfaction with care in the last 2 days of life were: caregiver perceptions of treatment with dignity and respect; adequate privacy; sufficient pain relief and decisions in line with the patient's wishes. A more in-depth exploration is required to understand the quality of, and satisfaction with, care in different settings as well as the factors that contribute to high/low satisfaction with care at the end-of-life.

ISSN: 09660410

From : <https://doi.org/10.1111/hsc.13053>

Hospice photography's effects on patients, families, and social work practice; by Charlotte Shuber, Adrian Kok.: Taylor and Francis, 2020, pp 19-41.

Journal of Social Work in End-of-Life and Palliative Care, vol 16, no 1, 2020, pp 19-41.

In this qualitative study, hospice photography is defined as photographs of hospice patients taken by social workers in the service of legacy construction. The study examined the influence of hospice photography on patients' end-of-life experiences, families' experiences with hospice and grief, and hospice social work practice. Six social workers were interviewed about the photographs they had previously taken of patients. The themes revealed were categorised as hospice photography's perceived and potential effects on patients, families, and practice and the role of smartphone technology. The data suggested that hospice photography may positively affect patients, families, and practice due to its reported ability to build and enhance rapport; facilitate therapeutic discussion; affirm patients' dignity, worth, and self-esteem; provide opportunities for bearing witness; and increase social workers' job satisfaction. Potential effects of the use of hospice photography in social work practice included the ability to tangibly contextualise the end-of-life experience; improve termination and closure; and provide comfort during the grieving process. (RH)

ISSN: 15524256

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

How do Admiral Nurses and care home staff help people living with dementia and their family carers prepare for end-of-life?; by Kirsten J Moore (et al.): Wiley, April 2020, pp 405-413.

International Journal of Geriatric Psychiatry, vol 35, no 4, April 2020, pp 405-413.

To explore current practice and the role of UK care homes and Admiral Nurses in helping people living with dementia and their family carers prepare for end-of-life, the authors conducted an online survey with all UK Admiral Nurses (59% response rate) and a random sample of Gold Standards Framework accredited care homes in England and Wales (38% response rate). Descriptive statistics were used to report survey findings. While respondents commonly discussed the progressive nature of dementia with people living with dementia and family carers, they less frequently spoke to people with dementia or carers about the nature of dementia as life shortening, terminal, or a disease you can die from. Admiral Nurses highlighted that where service models reduced continuity of care, opportunities for ongoing discussion and developing relationships that supported these discussions were reduced. Admiral Nurses and care homes raised concerns about conversations being left too late, when the person with dementia no longer had capacity to engage. There was a high level of agreement with all European Association of Palliative Care and National Institute for Health and Care Excellence (NICE) statements presented regarding end-of-life care planning and discussions. The survey found fragmentation across the service system, lack of continuity, and tensions regarding when these conversations should be initiated and by whom.

ISSN: 08856230

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

Palliative and end-of-life care's barriers for older adults; by Retno Indarwati, Rista Fauziningtyas, Gilang Dwi Kuncahyo, Dian Tristiana, Chong Mei Chan, Graeme D Smith.: Emerald, 2020, pp 72-80.

Working with Older People, vol 24, no 1, 2020, pp 72-80.

The authors explore the barriers to successful palliative and, more generally, end-of-life care (EOLC) for older adults in nursing homes. Nurses' views on the subject are also explored. The study is of a qualitative nature and it employs a phenomenological approach. In-depth interviews with 15 nurses who have taken care of older adults in a nursing home were conducted. The data were analysed using thematic content analysis. The study finds that barriers to effective EOLC include lack of knowledge, ineffectual communication and insufficient resources. (NL/RH)

ISSN: 13663666

From : <http://www.emeraldinsight.com/loi/wwop>

Philosophical dialogue in palliative care and hospice work; by Patrick Schuchter.: Policy Press, February 2020, pp 117-123.

International Journal of Care and Caring, vol 4, no 1, February 2020, pp 117-123.

Dealing with existential questions is a constitutive part of palliative care. Interestingly, if we admit that border situations at the end of life give rise to clearly 'philosophical' questions, in the contexts of practice, these questions are perceived (nearly) without any reference to explicit philosophical traditions or to 'philosophical practice'. Existential questions in palliative care are usually approached from other perspectives and within other organisational forms of reflection and dialogue (psychotherapy, supervision, spiritual care, moral case deliberation). This piece considers how philosophical dialogue and reflection could contribute to palliative care and hospice work.

ISSN: 2397883X

From : <https://policy.bristoluniversitypress.co.uk/journals/international-journal-of-care-and-caring>

Practice considerations for trauma-informed care at end of life; by Elizabeth S Ricks-Aherne, Cara L Wallace, Nancy Kusmaul.: Taylor and Francis, 2020, pp 313-329.

Journal of Social Work in End-of-Life and Palliative Care, vol 16, no 4, 2020, pp 313-329.

Trauma is widespread, and its symptoms can adversely impact well-being at the end of life, a time when hospice seeks to maximise quality of life. This article reviews research on trauma at end of life, provides an overview of trauma-informed principles, and explores possibilities for applying trauma-informed care through an illustrative case study of a patient at the end of life. The case discussion applies findings from the literature using Feldman's Stepwise Psychosocial Palliative Care model as a roadmap. As shown in the case study, trauma-related symptoms may complicate care, making it an important subject of clinical attention for interdisciplinary hospice team members. As part of this team, social workers are particularly well suited to provide more targeted interventions where indicated, though all members of the team should take a trauma-informed approach. Lastly, this article reflects on the need for organisations to take a systems-level approach when implementing trauma-informed care. The authors suggest implications for practice through a universal approach to trauma, and the need for trauma-specific assessments and interventions at end-of-life, along with areas for future research. (RH)

ISSN: 15524256

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

A theoretical exploration of live discharge from hospice for caregivers of adults with dementia; by Stephanie P Wladkowski, Cara L Wallace, Allison Gibson.: Taylor and Francis, 2020, pp 133-150.

Journal of Social Work in End-of-Life and Palliative Care, vol 16, no 2, 2020, pp 133-150.

Patients with dementia may be discharged from hospice if their condition stabilizes. The loss of professional support and an already complex grief process needs careful attention. A live discharge presents a unique experience for each hospice patient, caregiver and hospice team, which varies from traditional bereavement theories used to describe the grieving process. This article explores live discharge from hospice for caregivers of adults with dementia through a theoretical lens of Symbolic Interactionism (SI) and Attachment Theory (AT). The theories of SI and AT support and assist in understanding the experience of caregivers who lose hospice support due to ineligibility. In addition, caregivers watch the gradual deterioration and psychological loss of someone with dementia while they remain alive, described as an ambiguous loss. Ambiguous loss as a subset of traditional bereavement theories provides a framework for this exploration and provides a relevant illustration of the complex needs. This article concludes with implications for social work practice. It is important for hospice clinicians to be aware of current termination practices necessary to manage appropriate attachments, support the

symbolic meaning of the hospice experience, validate ambiguous losses, and maintain a sense of hope through a live discharge from hospice. (RH)

ISSN: 15524256

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

Value-based issues and policy change: medical assistance in dying in four narratives; by Nathalie Burlone.: Wiley, December 2020, pp 1096-1109.

Social Policy and Administration, vol 54, no 7, December 2020, pp 1096-1109.

In 2014, Québec became the first province in Canada to allow medical assistance in dying (MAID) by adopting the Act Respecting End-of-Life Care. This was, and still is, an important policy change. It involves a singular and highly moral issue that generated debates spanning over a longer period than that specific to the law's development and adoption. Using French and English newspapers' renderings of these debates in Québec between 2005 and 2015, this study deconstructs MAID's journey in the province into four periods, each characterized by a specific narrative: flexible precaution, legal hypocrisy, accountability imperative, and ineluctable adaptation. These four narratives allow us to better understand MAID's framing process as they reveal the underlying rationales of three overarching frames covering the 2005-2015 period: the legal frame, the social progress frame, and the service provision frame.

ISSN: 01445596

From : <https://doi.org/10.1111/spol.12587>

The voices of death doulas about their role in end-of-life care; by Deb Rawlings, Caroline Litster, Lauren Miller-Lewis (et al): Wiley, January 2020, pp 12-21.

Health and Social Care in the Community, vol 28, no 1, January 2020, pp 12-21.

The role of the 'death doula' has been described as one of companion, mentor and advocate for dying people and their families. Death Doulas have emerged as a relatively new role in this regard, however there is little clarity around how the role is enacted, and around the death doula role within health and social care systems. This Australian study aimed to explore the ambiguity of the role of death doulas in end-of-life care including the skills, training and experience of death doulas; how the role is communicated to the community; and the relationships to palliative care providers and other health professionals. People identifying as death doulas were invited to participate in an online survey between April and June 2018. Ethical approval was obtained. A descriptive cross-sectional study was conducted, and purposive sampling was used to survey death doulas registered with relevant training organisations, newsletters and email distribution lists. Questions were based on the researchers' previous findings about the role. 190 completed or partially completed surveys were received. Results showed diversity within, and some commonalities across the sample in terms of: training, experience and skill. Death doulas were found to have emerged not only as a response to the overwhelming demands on families and carers but also demands placed on health care professionals (including palliative care) at the end of life. They have identified gaps in health and social care provision, perhaps taking on tasks that health professionals don't have responsibility for. However the role and scope of practice of death doulas is not clear cut even within their cohort, which can then make it hard for patients and families when choosing a doula, especially as a lack of regulation and standardised training means that doulas are working without oversight and often in isolation. (JL)

ISSN: 09660410

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

2019

Community perspectives of end-of-life preparedness; by Davina Banner, Shannon Freeman, Damanpreet K Kandola (et al): Taylor and Francis, April 2019, pp 211-223.

Death Studies, vol 43, no 4, April 2019, pp 211-223.

While death is a universal human experience, the process of planning for death can be difficult and may be avoided altogether. To understand community perspectives of end-of-life preparedness, the authors undertook a multi-method study in Prince George, British Columbia, Canada exploring the experiences of 25 community members and 10 stakeholders engaged in end-of-life planning. In addition, card sorting activities and focused discussions with 97 older adults were undertaken to highlight perspectives and needs. Data were analysed using descriptive statistics and qualitative description. Overall, the participants perceived many benefits to being end-of-life prepared; however, few community members had engaged in formal planning. Key barriers include concerns about the accessibility and accuracy of information, discomfort when engaging in end-of-life conversations, and perceptions about the cost associated with engaging in formal legal or financial preparations. Areas for further research include the need for studies that capture the cultural dimensions of end-of-life

planning and explores the implementation and evaluation of community-based interventions to improve preparedness. (RH)

ISSN: 07481187

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

Comparing the attitudes of four groups of stakeholders from Quebec, Canada, toward extending medical aid in dying to incompetent patients with dementia; by Gina Bravo, Lise Trottier, Claudie Rodrigue (et al).: Wiley, July 2019, pp 1078-1086.

International Journal of Geriatric Psychiatry, vol 34, no 7, July 2019, pp 1078-1086.

The Canadian province of Quebec has recently legalised medical aid in dying (MAID) for competent patients who satisfy strictly defined criteria. The province is considering extending the practice to incompetent patients. In this study the authors compared the attitudes of four groups of stakeholders toward extending MAID to incompetent patients with dementia. The study conducted a province-wide postal survey in random samples of older adults, informal caregivers of persons with dementia, nurses and physicians caring for patients with dementia. Clinical vignettes featuring a patient with Alzheimer's disease were used to measure the acceptability of extending MAID to incompetent patients with dementia. Vignettes varied according to the stage of the disease (advanced or terminal) and type of request (written or oral only). The generalised estimating equation (GEE) approach was used to compare attitudes across groups and vignettes. Response rates ranged from 25% for physicians to 69% for informal caregivers. In all four groups the proportion of respondents who felt it was acceptable to extend MAID to an incompetent patient with dementia was highest when the patient was at the terminal stage, showed signs of distress and had written a MAID request prior to losing capacity. In those circumstances this proportion ranged from 71% among physicians to 91% among informal caregivers. Overall there was found to be high support in Quebec for extending the current MAID legislation to incompetent patients with dementia who had reached the terminal stage, appeared to be suffering and had requested MAID in writing while still competent. (JL)

ISSN: 08856230

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

A comparison of the influence of anticipated death trajectory and personal values on end-of-life care preferences: a qualitative analysis; by Katherine P Supiano, Nancy McGee, Kara B Dassel, Rebecca Utz.: Taylor and Francis, May-June 2019, pp 247-258.

Clinical Gerontologist, vol 42, no 3, May-June 2019, pp 247-258.

The authors examined anticipated preferences for end-of-life (EOL) care in healthy older people in the context of various terminal disease scenarios, to explore the relationship between personal values and diseases and conditions that would influence EOL care choices. 365 respondents in an American national sample of healthy older adults completed a survey on their anticipated preferences for end-of-life (EOL) care. Qualitative Descriptive Analysis was used to derive themes and the relationship between EOL preference themes and personal value themes. Reluctance to burden close others was the most frequently voiced personal value across all conditions affecting EOL preferences, followed by the personal value of quality of life. Concern about whether one's wishes would be honoured was more commonly voiced in the context of hypothetical, prospective terminal cancer than in neurological conditions. Respondents who voiced desire for autonomy in how they would die clearly attributed extreme pain as the primary influence on EOL preferences. Comprehensive assessment of patient personal values should include consideration of particular chronic disease scenarios and death trajectories in order to fully inform EoL preferences. Because personal values do influence EOL preferences, care should be taken to ascertain patient values when presenting diagnoses, prognoses and treatment options. In particular, patients and families of patients with progressive neurological diseases will likely face a time when the patient cannot self-represent EOL wishes. Early discussion of values and preferences, particularly in the context of cognitive disease, is vital to assure patient-directed care. (RH)

ISSN: 07317115

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

Conceptualizing "project resiliency": a qualitative study exploring the implementation of coordinated care within a context of system change; by Laura M Holdsworth.: Emerald, 2019, pp 163-172.

Journal of Integrated Care, vol 27, no 2, 2019, pp 163-172.

In order to meet the multidimensional needs of patients health services are increasingly implementing complex programmes of care through partnerships between different sectors. The purpose of this paper was to explore the implementation process of a complex, multi-innovative regional health and social care partnership to coordinate end-of-life care in the South East of England. The study adopted a pragmatic, pluralist design using primarily qualitative methods including observations, interviews, focus group and document review. Implementation theory provided the research framework. While progress was made towards greater

collaboration in the provision of end-of-life care, regional coordination of care among the 13 partner organisations was not achieved as envisioned. Low engagement stemming from national health system changes delayed decision making and shifted partners' priorities. Individual stakeholder interest and motivation carried the elements that were successful. The external political and economic environment hindered the involvement of some of the partners. It is suggested that a concept of 'project resiliency' is particularly important for complex, multi-organisational projects which are implemented over time and by multiple stakeholders from different sectors. Future research should look further at what contributes to project resiliency and whether it might be operationalised so that projects can develop resilient factors for success. (JL)

ISSN: 14769018

From : <http://www.emeraldinsight.com/loi/jica>

Does informal care impact utilisation of home-based formal care services among end-of-life patients?: A decade of evidence from Ontario, Canada; by Zhuolu Sun, Denise N Guerriere, Claire de Oliveira, Peter C Coyte.: Wiley, March 2019, pp 437-448.

Health and Social Care in the Community, vol 27, no 2, March 2019, pp 437-448.

Understanding how informal care affects formal care utilisation for home-based end-of-life patients is of great relevance to policy and practice. This paper aims to assess the relationship between informal and formal home care among home-based end-of-life patients, and how this relationship has changed over the last decade and over the end of life trajectory. This study focuses on informal care provided by family members or friends, and three types of home-based formal care services: care by personal support workers, physician visits, and nurse visits. Using survey data collected in a home-based end-of-life care programme in Ontario, Canada from 2005 to 2016, a two-part utilisation model analysing both the propensity to use each type of formal care and the amount of formal care received by patients, is built. The results suggest that informal care is a substitute for care by personal support workers, but a complement to physician visits and nurse visits. In the case of nurse visits, an increased complementary effect is observed in more recent years. For home-based physician and nurse visits, the complementary effect grows with patient's proximity to death. These results highlight the complexity of the relationship between informal and formal care among home-based end-of-life patients. Decision-makers need to take into account the relationship between informal care and different types of formal services when introducing future policies. (RH)

ISSN: 09660410

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

The need for flexibility when negotiating professional boundaries in the context of home care, dementia and end of life; by Ruth Abrams, Tushna Vandrevala, Kritika Samsi, Jill Manthorpe.: Cambridge University Press, September 2019, pp 1976-1995.

Ageing and Society, vol 39, no 9, September 2019, pp 1976-1995.

Professional boundaries may help care staff to clarify their role, manage risk and safeguard vulnerable clients. Yet there is a scarcity of evidence on how professional boundaries are negotiated in a non-clinical environment (e.g. the home) by the home-care workforce in the context of complex care needs (e.g. dementia, end-of-life care). Through analysis of semi-structured interviews, the authors investigated the experiences of home-care workers (N = 30) and their managers (N = 13) working for a range of home-care services in the South-East and London regions of England in 2016-17. Findings from this study indicate that home-care workers and their managers have clear perceptions of job role boundaries; yet these are modified in dementia care, particularly at end of life which routinely requires adaptability and flexibility. As a lone worker in a client's home, there may be challenges relating to safeguarding and risk to both clients and workers. The working environment exacerbates this, particularly during end-of-life care, where emotional attachments to both clients and their family may affect the maintenance of professional boundaries. There is a need to adopt context-specific, flexible and inclusive attitudes to professional boundaries, which reconceptualise these to include relational care and atypical workplace conventions. Pre-set boundaries which safeguard clients and workers through psychological contracts may help to alleviate to some extent the pressure of the emotional labour undertaken by home-care workers. (RH)

ISSN: 0144686X

From : <http://www.cambridge.org.aso>

Thinking about the end of life when it is near: a comparison of German and Portuguese centenarians; by Kathrin Boerner, Daniela S Jopp, Kyungmin Kim (et al): Sage, March 2019, pp 265-285.

Research on Aging, vol 41, no 3, March 2019, pp 265-285.

This study examined the extent to which thinking of and planning for the end of life (EOL) is widespread among German and Portuguese centenarians, and whether patterns of EOL views are shaped by cultural and individual characteristics. A significant proportion of centenarians in both countries reported not thinking about the EOL,

not believing in the afterlife, and not having made EOL arrangements. Latent class analysis identified three EOL patterns: Class 1 (EOL thoughts with EOL arrangements and afterlife beliefs), Class 2 (EOL arrangements and afterlife beliefs without EOL thoughts), and Class 3 (Overall low endorsement of EOL items). The proportion of Portuguese centenarians was higher in Class 1, and of German centenarians higher in Classes 2 and 3. Centenarians' demographic, social, and health characteristics were significantly different across EOL patterns. As lack of EOL planning can result in poor EOL quality, enhancing communication among centenarians, family, and health-care professionals seems imperative. (RH)

From : <http://www.journals.sagepub.com/home/roa>

Volunteer involvement in the organisation of palliative care: a survey study of the healthcare system in Flanders and Dutch-speaking Brussels, Belgium; by Steven Vanderstichelen, Joachim Cohen, Yanna van Vesemael (et al.): Wiley, March 2019, pp 459-471.

Health and Social Care in the Community, vol 27, no 2, March 2019, pp 459-471.

Ageing populations increasingly face chronic and terminal illnesses, emphasising the importance of palliative care and quality of life for terminally ill people. Facing resource constraints in professional healthcare, some governments expect informal caregivers such as volunteers to assume a greater share of care provision. We know volunteers are present in palliative care and perform many roles, ranging from administration to providing companionship. However, we do not know how involved they are in the organisation of care, and how healthcare organisations appraise their involvement. To address this, this study provides an extensive description of the involvement of volunteers who provide direct patient palliative care across the Flemish healthcare system in Belgium. This study conducted a cross-sectional postal survey of 342 healthcare organisations in Flanders and Brussels in 2016, including full population samples of palliative care units, palliative day care centres, palliative home-care teams, medical oncology departments, sitting services, community home-care services, and a random sample of nursing homes. Volunteer involvement was measured using Sallnow and Paul's power-sharing model, which describes five hierarchical levels of engagement, ranging from being informed about the organisation of care, to autonomy over certain aspects of care provision. Response was obtained for 254 (79%) organisations. Volunteers were often informed about and consulted regarding the organisation of care, but healthcare organisations did not wish for more autonomous forms of volunteer involvement. Three clusters of volunteer involvement were found: "strong involvement" (31.5%), "restricted involvement" (44%), and "uninvolved" (24.5%). Degree of involvement was found to be positively associated with volunteer training ($p < 0.001$) and performance of practical ($p < 0.001$) and psychosocial care tasks ($p < 0.001$). Dedicated palliative care services displayed a strong degree of volunteer involvement, contrary to generalist palliative care services, suggesting volunteers have a more important position in dedicated palliative care services. A link is found between volunteer involvement, training and task performance. (RH)

ISSN: 09660410

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

Working with colleagues and other professionals when caring for people with dementia at the end of life: home care workers' experiences; by Jill Manthorpe, Tushna Vandrevala, Ruth Abrams, Kritika Samsi.: Policy Press, November 2019, pp 567-583.

International Journal of Care and Caring, vol 3, no 4, November 2019, pp 567-583.

Caring for people with dementia often necessitates inter-professional and inter-agency working, but there is limited evidence of how home care staff work as a team and with professionals from different agencies. Through analysis of semi-structured interviews, the research explores the experiences of home care workers ($n = 30$) and managers of home care services ($n = 13$) in England (2016-17). Both groups sought to collaboratively establish formal and informal practices of teamwork. Beyond the home care agency, experiences of interacting with the wider health and care workforce differed. More explicit encouragement of support for home care workers is needed by other professionals and their employers. (RH)

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From : <https://policy.bristoluniversitypress.co.uk/journals/international-journal-of-care-and-caring>

2018

The "medicalized death": dying in the hospital; by Benyamin Schwarz, Jacquelyn J Benson.: Taylor and Francis, July-December 2018, pp 379-430.

Journal of Housing for the Elderly, vol 32, nos 3-4, July-December 2018, pp 379-430.

This article is part of a larger study dedicated to the place of death and dying. Its focus is on the "medicalized death" of older people who died in hospitals in Israel and the United States, and is based on the experiences of four family members who cared for them at the end of their lives. In-depth interviews were conducted with each participant, and narrative analysis methods were utilized to identify themes in the data. In the findings section,

participant accounts are presented as individual monologues, each followed by the authors' theoretical commentary. Despite the fact that the process of dying in a hospital is often depicted in the media as being fraught with excessive and aggressive procedures, the cases described in this article suggest there is marked ambiguity and contradiction experienced by caregivers and patients regarding the hospital setting for the process of dying. In some cases, the hospital was perceived as a preferred place for dying, because it often reduced caregiver strain. However, participants also remarked on many undesirable aspects about hospital deaths, including dying in the company of strangers; the lack of empathy from physicians; and existential dilemmas about the withdrawal of treatment. (RH)

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

Care pathways for the dying patients: physician perspective; by Benyamin Schwarz, Jacquelyn J Benson.: Taylor and Francis, July-December 2018, pp 431-461.

Journal of Housing for the Elderly, vol 32, nos 3-4, July-December 2018, pp 431-461.

The overriding care philosophy in medicine is to prevent death, rather than focus on dying. However, increasing longevity in most parts of the world has resulted for many people in prolonged periods of declining health toward the end of life. This has complicated our understanding of when the dying process begins. As a result, there has been a growing movement within society and among health care systems to focus on finding ways to contribute to patients' quality of life just before they die. The modern hospice and palliative care movement has gained distinction as an alternative way of looking at health care. These care philosophies perceive dying as a natural part of the life cycle. Staff members prioritise comfort and quality of life over longevity. However, the goals of hospice and palliative care are often misunderstood by the public. This article is based on interviews with two palliative care physicians that were conducted as part of a larger study about the place of dying. The goal of these interviews was to obtain the physician perspective of dying at a hospital, at home, and in an institutional setting, as well as to provide readers greater clarity on the palliative and hospice care perspectives within these contexts. (RH)

ISSN: 02763893

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

Caregiver informational support in different patient care settings at end of life; by Susan A Lavalley.: Taylor and Francis, April-June 2018, pp 97-112.

Home Health Care Services Quarterly, vol 37, no 2, April-June 2018, pp 97-112.

Family members and friends who care for terminally ill loved ones face many complicated tasks including providing direct patient care, communicating with clinicians and managing the logistical demands of daily activities. They require instructive information at all points in the illness process and across several settings where patients receive end-of-life care. This study examined how the setting where a patient receives end-of-life care affects caregivers' informational support needs by thematically analysing data from caregiver interviews and clinical observations. Caregivers providing care for patients at home received informational support related to meeting patients' mobility, medication and nutritional needs. Caregivers who provided care remotely received informational support to navigate transitions between patient care settings or long-term care arrangements, including financial considerations and insurance logistics. The findings document that interventions designed to enhance information for caregivers should account for caregiving context and that health care providers should proactively and repeatedly assess caregiver information needs related to end-of-life patient care. (JL)

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

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>

Change in VA community living centers 2004-2011: shifting long-term care to the community; by Kali S Thomas, Danielle Cote, Rajesh Makineni (et al.): Taylor and Francis, March-April 2018, pp 93-108.

Journal of Aging and Social Policy, vol 30, no 2, March-April 2018, pp 93-108.

The United States Department of Veterans Affairs (VA) is facing pressures to rebalance its long-term care system. Using VA administrative data from 2004-2011, the authors describe changes in the VA's nursing homes (called Community Living Centers [CLCs]) following enactment of directives intended to shift CLCs' focus from providing long-term custodial care to short-term rehabilitative and post-acute care, with safe and timely discharge to the community. However, a concurrent VA hospice and palliative care expansion resulted in an increase in hospice stays, the most notable change in type of stay during this time period. Nevertheless, outcomes for Veterans with non-hospice short and long stays, such as successful discharge to the community, improved. The authors discuss the implications of their results for simultaneous implementation of two initiatives in VA CLCs. (RH)

ISSN: 08959420

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

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 in long-term care: perspectives from sexual and gender minority older adults about their fears and hopes for end of life; by Katherine Kortess-Miller, Jessica Boule, Kimberley Wilson, Arne Stinchcombe.: Taylor and Francis, April-September 2018, pp 209-224.

Journal of Social Work in End-of-Life and Palliative Care, vol 14, nos 2-3, April-September 2018, pp 209-224.

As lesbian, gay, bisexual, transgender and queer (LGBTQ+) communities age, many individuals expect a need to enter the long-term care system toward the end of life. Not unlike most ageing Canadians, this anticipation is met with concern and fear. However, previous research suggests that older LGBTQ+ individuals have unique fears, often related to personal safety and discrimination. This qualitative study examined the hopes and fears of older LGBTQ+ adults considering long-term care as they face end of life. Data were collected from three focus groups in Ontario, Canada, and analysed using inductive thematic analysis. Specific and frequent reference to fear of entering long-term care homes was common across all focus groups. The participants anticipated social isolation, decreased independence and capacity for decision-making, increased vulnerability to LGBTQ+-related stigma, as well as exposure to unsafe social and physical environments. The results from this study emphasise the need for palliative care specialists and long-term care home staff to address the unique health needs of older LGBTQ+ adults nearing the end of life, in order to work toward allaying fears and creating supportive and inclusive long-term care environments. (RH)

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

End of life care: resources to strengthen support; by Alastair Macdonald.: Hawker Publications, January-February 2018, pp 28-31.

Journal of Dementia Care, vol 26, no 1, January-February 2018, pp 28-31.

As more people die with dementia, end of life care discussions are growing in importance. The author and colleagues report on their study and explain how co-designing new resources could help to strengthen support at the end of life. They use findings from the Supporting Excellence in End of life care in Dementia programme (SEED study), which has developed a nurse-led intervention which has been tested in primary care settings. The authors have used this model to dementia nurse specialists work more effectively with patients and their families and improve the knowledge and skills of patients' health care teams. They outline how they developed a new resource by mapping existing resources, which led them to use a co-design approach to develop a prototype

Care Plan Guide (CPG). This was tested in co-design workshops with some of the support workers and nurses who would be using the resource. (RH)

ISSN: 13518372

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

Filling the void: hospital palliative care and community hospice: a collaborative approach to providing hospital bereavement support; by Cathy J Silloway, Toni L Glover, Brian J Coleman, Sheri Kittelson.: Taylor and Francis, April-September 2018, pp 153-161.

Journal of Social Work in End-of-Life and Palliative Care, vol 14, nos 2-3, April-September 2018, pp 153-161.

Bereavement services are often provided as components of hospice and palliative care plans, including emotional, psychosocial and spiritual support provided to individuals and families to assist with grief, loss and adjustment after the death of a loved one. Patient- and family-centred care is a hallmark of palliative care. Moreover, bereavement counselling is offered as a hospice care benefit that is covered by Medicare and various private insurance plans in the US. However, not all hospital-based palliative care programmes offer bereavement support. This article describes an innovative bereavement programme designed to offer support to individuals whose loved one died in the hospital while receiving palliative care. The bereavement team, including clinical professionals from the inpatient palliative care team and two community hospices, developed the University of Florida (UF) Health Bereavement Program. The interprofessional team includes social workers, volunteers, chaplains, nurses, nurse practitioners and physicians. The Bereavement Program incorporates grief support workshops, follow-up with participants via postal mail at timed intervals, website access to grief resources, staff education, and an annual evening of remembrance. Finally, interagency collaboration has extended the reach of bereavement services beyond UF Health into the community at large. This model of provision serves as an example for other hospital-based palliative care services. (RH)

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

Life, death and the stories in between: storytelling in geriatric medicine; by Bryan H McGill.: British Geriatrics Society, February 2018, pp 6-8.

BGS Newsletter, no 64, February 2018, pp 6-8.

Storytelling has many roles within society, including in geriatric medicine. It unites us, imparting wisdom from one generation to the next, and gives us a glimpse into the lives of those dearest to us. It can also be used to reduce anxiety when faced with difficult subjects such as end of life decisions and Advance Care Plans. (RH)

ISSN: 17486343

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

"Magic happens here": environmental serenity in residential hospice care; by Deborah P Waldrop, Jacqueline M McGinley.: Taylor and Francis, July-December 2018, pp 462-478.

Journal of Housing for the Elderly, vol 32, nos 3-4, July-December 2018, pp 462-478.

The authors explore the unique interaction between the care that is provided in, and the environmental features of, hospice residences. Interviews with 40 professionals from eight hospice residences focused on elements of care. Visual content analysis was conducted with 187 photographs of internal and external environments. Three themes illuminated residential care as: patient-family-centred, flexible, and comfort-focused. Six environmental features are described as: site and context; nature connectivity; arrival spaces; communal spaces; private spaces; and transitional spaces. The interaction between residential care and the environmental features creates environmental serenity. (RH)

ISSN: 02763893

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

The motivations and consequences of dying at home: family caregiver perspectives; by Jacquelyn J Benson, Benjamin Schwarz, Ruth Brent Tofie, Debra Parker Oliver.: Taylor and Francis, July-December 2018, pp 278-336.

Journal of Housing for the Elderly, vol 32, nos 3-4, July-December 2018, pp 278-336.

Although there is ample research suggesting that individuals prefer to die at home, the realities of a home death experience, from the perspective of family members, are not well understood. The authors examine this gap in knowledge via a narrative analysis about the process of dying at home. Five family caregivers participated in semi-structured interviews about their experiences witnessing and supporting the end-of-life process of an older family member who died at home. Their stories paint a vivid picture about the motivations and consequences of the experience, including themes such as caregivers' immense feelings of uncertainty regarding their caregiving abilities and decision making, the significance of the home environment as a symbol of comfort and security, the influence of family and social networks, and "dying well" as a social justice issue. Overall, the caregivers' narratives support the notion that being at home is considered an essential aspect of "dying well". However, the

narratives also demonstrate that dying at home presents many challenges for family members, especially to those with limited resources and social support. Thus, the authors caution against viewing the home death as a proxy for a good death. (RH)

ISSN: 02763893

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

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>

Navigating the liminal space: trauma, transition, and connection in bereaved carers' experiences of specialist palliative care in Western Sydney; by Kristin Bindley, Anne May, Wendy Pavlek (et al.): Taylor and Francis, April-September 2018, pp 225-239.

Journal of Social Work in End-of-Life and Palliative Care, vol 14, nos 2-3, April-September 2018, pp 225-239.

Caregiving at the end of life has been associated with a range of physical, spiritual, social and psychological outcomes, and influenced by encounters with providers of specialist palliative care. This qualitative study explores experiences of bereaved carers of people with a life-limiting illness, in the context of care provided through a Western Sydney supportive and palliative care service. Thirteen bereaved caregivers participated in semi-structured, in-depth interviews. Transcripts were analysed using a thematic approach, informed by thematic networks. Four domains appeared to mediate carer experiences: confrontations with trauma, suffering and death; navigating transitions and boundaries and the caregiving role as liminal space; encountering connection in formal care contexts; and negotiating system issues. This study is one of the first to explore caregiver experiences within a low socioeconomic population in Western Sydney, and to provides a nuanced understanding of factors which may shape experiences of palliative care. Findings suggest the need for ongoing attention to the cultivation of skilful practitioners who are mindful of companion caregivers' needs, and in a manner attuned to the potential for trauma in the context of expected death. Additionally, findings call for investment in specialist sites of care alongside greater attention to public health approaches to palliative care. (RH)

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

Place of death and dying: introduction; by Benjamin Schwarz, Jacquelyn J Benson.: Taylor and Francis, July-December 2018, pp 267-277.

Journal of Housing for the Elderly, vol 32, nos 3-4, July-December 2018, pp 267-277.

This special issue of Journal of Housing for the Elderly focuses on the environments of dying, death and caregiving at end of life for older people. This article introduces four articles by researchers at the University of Missouri about a project which considers older patients', family caregivers' and physicians' perspectives on the process of dying in three different environments: home, nursing home, and hospital. (RH)

ISSN: 02763893

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

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>

The Rosalie Wolf Memorial Lecture: abuse-free care in a world of age-friendly health systems; by Terry Fulmer.: Taylor and Francis, March-July 2018, pp 167-175.

Journal of Elder Abuse and Neglect, vol 30, no 3, March-July 2018, pp 167-175.

The author is President of the John A Hartford Foundation (JAHF) in New York City, which was founded in 1929 and dedicated to improving older people's care, including eradicating all forms of elder mistreatment. The Foundation allows serious gaps in older people's quality of care to be identified, also to take action through grantmaking, convening and using strategies and tactics that spread best geriatric care models and practice. Under current strategic initiatives, the JAHF has three main areas of emphasis, which the author describes: age-friendly health systems; support for family caregivers; and improving serious illness and end-of-life care. When there are failures in any of these three systems, the likelihood of elder mistreatment increases proportionately. He concludes that it is "time for an abuse-free society and age-friendly health systems". (RH)

ISSN: 08946566

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

Rural residents' perspectives on the rural 'good death': a scoping review; by Susanne Rainsford, Roderick D MacLeod, Nicholas J Glasgow (et al.): Wiley, May 2018, pp 273-294.

Health and Social Care in the Community, vol 26, no 3, May 2018, pp 273-294.

The 'good death' is one objective of palliative care, with many 'good death' viewpoints and research findings reflecting the urban voice. Rural areas are distinct and need special consideration. This scoping review identified and charted current research knowledge on the 'good' rural death through the perspectives of rural residents, including rural patients with a life-limiting illness, to identify evidence and gaps in the literature for future studies. A comprehensive literature search of English language articles (no date filter applied) was conducted in 2016 (2 January to 14 February) using five library databases (PubMed, CINAHL, Scopus, PsycINFO and Web of Science). Reference lists of included articles, recent issues of eight relevant journals and three grey literature databases were also hand-searched. Twenty articles (for 17 studies and one systematic review) were identified after a two-phase screening process by two reviewers, using pre-determined inclusion criteria. Data from each study were extracted and charted; a thematic analysis was used of the included articles' content, and with a quantitative analysis of the scoping review. These papers revealed data collected from rural patients with a life-limiting illness and family caregivers, rural healthcare providers, the wider rural community, rural community leaders and rural health administrators and policy makers. Rural locations were heterogeneous. Residents from developed and developing countries believe a 'good death' is one that is peaceful, free of pain and without suffering; however, this is subjective and priorities are based on personal, cultural, social and religious perspectives. Currently, there is insufficient data to generalise rural residents' perspectives and what it means for them to die well. Given the extreme importance of a 'good death', there is a need for further studies to elicit rural patient and family caregiver perspectives. (RH)

ISSN: 09660410

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

Staying out of the closet: LGBT older adults' hopes and fears in considering end-of-life; by Kimberley Wilson, Katherine Kortess-Miller, Arne Stinchcombe.: Cambridge University Press, March 2018, pp 22-31.

Canadian Journal on Aging, vol 37, no 1, March 2018, pp 22-31.

There is increasing diversity among Canada's older population today. The purpose of this study was to help fill research gaps on ageing and end-of-life among Canada's LGBT (Lesbian, gay, bisexual and transgender) older population. Through focus groups the authors sought to better understand the lived experience of older LGBT individuals and to examine their concerns associated with end-of-life. The study analysis highlighted the idea that identifying as LGBT matters when it comes to ageing and end-of-life care. In particular, gender identity and sexual orientation matter when it comes to social connections, in the expectations individuals have for their own care, and in the unique fear related to staying out of the closet and maintaining identity throughout the process. This study underscores the need to consider gender identity and sexual orientation at end-of-life. In particular, recognition of intersectionality and social locations is crucial to facilitating positive ageing experiences and end-of-life care. (JL)

ISSN: 07149808

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

Talking about dying: how to begin honest conversations about what lies ahead; by Sarah-Jane Bailey, Kacey Cogle, Royal College of Physicians - RCP. London: Royal College of Physicians, October 2018, 19 pp.

Based on conversations with doctors at all levels, patients and carers, and medical organisations, this report reveals the barriers to talking about death identified by doctors, the first being culture, that is, the perception of failure to prevent a death. Second is confidence: feeling uncomfortable about initiating conversations with patients about the future. Third, practicalities: confusion over whether hospital doctors or the patient's GP should be having the conversation, also reluctance to begin conversations. The report offers solutions and resources to help, including a "mythbusting" section, debunking common but erroneous beliefs. Four English hospitals leading the way in supporting end-of-life care conversations have contributed good practice case studies. The evidence shows that patients who have had conversations about advance care planning (ACP) and have end-of-life care plans in place have a better experience than those for whom the conversations come in the final days or hours of life when they can seem unexpected to patients and carers. (RH)

From : <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead>

Unique needs: Salvation Army officers in retirement and end-of-life care; by Bruce Allen Stevens, Rhonda Shaw, Peter Bewert (et al.): Taylor and Francis, 2018, pp 63-77.

Journal of Religion, Spirituality and Aging, vol 30, no 1, 2018, pp 63-77.

The present study focused on retirement as a life transition for clergy and those who serve in the church. The study looked at whether being ordained, having a respected leadership role in the church and serving God brings some unique dynamics to this transition. In particular the article aimed to identify such factors using a large sample of Australian Salvation Army officers. These factors included financial concerns, life satisfaction and realism about the challenges of ageing, and attitudes to death and dying and the difference that faith in Christ makes (JL)

ISSN: 15528030

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

Welcoming death: exploring pre-death grief experiences of caregivers of older adults with dementia; by Cynthia Hovland.: Taylor and Francis, October-December 2018, pp 274-290.

Journal of Social Work in End-of-Life and Palliative Care, vol 14, no 4, October-December 2018, pp 274-290.

The death of an older person with dementia often has an uncertain dying trajectory and has been referred to as "the long goodbye". Researchers have found both positive and negative outcomes of pre-death grief for caregivers of individuals with chronic illnesses. This qualitative study explored the end-of-life experiences for 36 bereaved family caregivers of older adults with dementia in Michigan and Cleveland, Ohio, focusing on understanding their experiences with pre-death grief. These caregivers shared experiences with the phenomenon of "welcoming death". The findings highlight the primary reasons they anticipated, accepted or wished for the death of their family member with dementia. With the overarching goal of improving bereavement outcomes and reducing feeling of guilt, inclusion of pre-death grief support services throughout the caregiving process are recommended. (RH)

ISSN: 15524256

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

2017

Advance decisions: issues of autonomy, identity and efficacy; by Sue Wilkinson.: Emerald, 2017, pp 4-12.

Working with Older People, vol 21, no 1, 2017, pp 4-12.

The Mental Capacity Act 2005 came into force in 2007, since when there has been statutory provision for making a legally binding advance decision. This paper introduces Advance Decisions, to indicate reasons for their low uptake, and examine fundamental issues that can inform the development of policy and practice in this area. The paper discusses findings from a research project with the charity Compassion in Dying (analysing calls to its telephone helpline) and practical experience of working with the charity Advance Decisions Assistance (helping people write Advance Decisions and training healthcare professionals). Older people themselves identify the issues of autonomy, identity and efficacy as key challenges in writing Advance Decisions and having them respected. (RH)

ISSN: 13663666

From : www.emeraldinsight.com/loi/wwop

Advancing care: research with care homes; by Kristina Staley, Tara Lamont, Tannaze Tinati, Tansy Evans, National Institute for Health Research - NIHR; NIHR Dissemination Centre.: National Institute for Health Research, July 2017, 44 pp (Themed review).

More than 400,000 older people live in 19,000 independently owned care homes in the UK. The National Institute for Health Research (NIHR) has funded this themed research review, which focuses on studies wholly or partly funded by the NIHR on three main themes relating to the care of care home residents. First, Living well, on maintaining good health and quality of life, also considers routine health checks, preventing avoidable health problems. improving nutrition, and finding better ways to reduce depression and pain and manage incontinence. Second, Ageing Well, concerns managing long-term conditions associated with ageing, particularly finding ways to improve the care of those living with dementia; identifying the needs of ageing residents with multiple serious conditions; and strategies to reduce medication errors, and avoid hospital admissions. Lastly, Dying Well, on ensuring a good quality end of life, looks at preferred place of death, supporting the very old at the end of life, and end of life care of people with dementia. Summaries of the studies and associated references are provided. Further areas of study to build on what has been learned to date are suggested, given a new and relatively undeveloped research base. (RH)

From : <http://www.dc.nihr.ac.uk/themed-reviews/advancing-care.htm>

Comfort care plans: a collaborative project; by Julie Young, Sue Gilbertson, Jenny Reid.: Hawker Publications, November-December 2017, pp 18-20.

Journal of Dementia Care, vol 25, no 6, November-December 2017, pp 18-20.

What is the best way to implement person-centred end of life care for people with dementia? The authors describe the development of "comfort care plans", which involved a partnership between Northumberland County Behaviour Support Service (NCBSS) and HospiceCare North Northumberland. They used the Newcastle Model (developed by Ian James) to support the development of the concept of comfort as a need to be met with a personalised care plan constructed around this need. Maslow's hierarchy of needs provided a structure to ensure that physical needs as well as emotional needs were identified and met. A case study illustrates how a comfort care plan works in practice. (RH)

ISSN: 13518372

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

Dementia caregivers and live discharge from hospice: what happens when hospice leaves?.: Taylor and Francis, February-March 2017, pp 138-154.

Journal of Gerontological Social Work, vol 60, no 2, February-March 2017, pp 138-154.

Hospice offers holistic support for individuals living with terminal illness and their caregivers. Some individuals receiving hospice services experience a slower decline in health than expected, resulting in a 'live discharge' from hospice. A live discharge affects both patient and caregiver(s). This study explored the experiences of 24 American caregivers of adults with dementia who experienced a live discharge from hospice. Findings emphasise the comprehensive services covered under the Medicare Hospice benefit and those lost after a live discharge. Implications for social workers supporting caregivers are discussed, including the need to view the patient-caregiver unit during a live discharge. (RH)

ISSN: 01634372

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

Dying well with an intellectual disability and dementia; by Kathryn Service, Karen Watchman.: Hawker Publications, July/August 2017, pp 28-31.

Journal of Dementia Care, vol 25, no 4, July/August 2017, pp 28-31.

As more people with learning disabilities live into old age, the prevalence of dementia in this group is increasing. The authors and colleagues examine the challenges to dementia practice presented by intellectual disability. (RH)

ISSN: 13518372

From : www.careinfo.org

End-of-life conversations and hospice placement: association with less aggressive care desired in the nursing home; by Joann P Reinhardt, Deirdre Downes, Verena Cimarolli, Patricia Bomba.: Taylor and Francis, January-March 2017, pp 61-81.

Journal of Social Work in End-of-Life and Palliative Care, vol 13, no 1, January-March 2017, pp 61-81.

Education about end-of-life care and treatment options, communication between family and health care providers, and having advance directives and medical orders in place are important for older adults with chronic, progressive decline and end-stage disease who spend their last days in the nursing home. This US study used retrospective data (6 months before death) of long-stay nursing home decedents (N=300) taken from electronic

health records to capture the end-of-life experience. Findings showed for almost all decedents, Do Not Resuscitate and Do Not Intubate orders were in place, and just over one-half had Do Not Hospitalize and No Artificial Feeding orders in place. A small proportion had No Artificial Hydration or No Antibiotic orders in place. Overall, there was congruence between documented medical orders and treatment received. Findings showed that use of hospice and discussions about particular life-sustaining treatments each had significant associations with having less aggressive medical orders in place. These results can inform best practice development to promote high quality, person-directed, end-of-life care for nursing home residents.

ISSN: 15524256

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

Hospice as experiences by LTC nurses and their perception of resident experiences; by Jennifer Annette Aeling, Tammi Vacha-Haase.: Taylor and Francis, October-December 2017, pp 367-377.

Clinical Gerontologist, vol 40, no 5, October-December 2017, pp 367-377.

This qualitative study aimed to better understand long-term care (LTC) nursing staff's experience in hospice services, their perceptions of residents choosing hospice services. Also considered was understanding differences LTC nurses have experienced regarding resident deaths. The study used Interpretative Phenomenological Analysis (IPA) to extract themes and sub-themes from 10 interviews with LTC nursing staff. Content analysis was also utilised to extract one noteworthy concept, which was a comparison of two resident deaths, with and without use of hospice services. Three main themes were extracted from the data: LTC nursing participants' positive view of hospice; their perception that residents view hospice very negatively; and why residents choose hospice services. Participants also identified aspects of a "bad" or "good" death, with clear relationships noted when using hospice services. Findings identified a difference between the LTC nursing staff's positive view of hospice and their belief that their residents view hospice services very negatively. According to these nurses' experiences, to most residents, hospice meant something rather negative and feared. Therefore, an intervention which provides information about hospice services for the LTC resident population may increase the percentage of older adults who use hospice services. (RH)

ISSN: 07317115

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

Hospice volunteers: bridging the gap to the community?; by Sara M Morris, Sheila Payne, Nick Ockenden, Matthew Hill.: Wiley, November 2017, pp 1704-1713.

Health and Social Care in the Community, vol 25, no 6, November 2017, pp 1704-1713.

Current demographic, policy and management changes are a challenge to hospices to develop their volunteering practices. A team from the International Observatory on End of Life Care and the Institute for Volunteering Research researched volunteering in British hospices, to explore good practice in volunteer involvement and to identify ways of improving care through developing volunteering. This project comprised a narrative literature review, a survey of volunteer managers, and organisational case studies selected through purposive diversity sampling criteria. A total of 205 staff, volunteers, patients and relatives were interviewed across 11 sites in England in 2012. This article focuses on one of the findings - the place that volunteers occupy between the hospice and the community beyond its walls. External changes and pressures in society were affecting volunteer management, but were viewed as requiring a careful balancing act to retain the 'spirit' of the hospice philosophy. Honouring the developmental history of the hospice was vital to many respondents, but viewed less positively by those who wished to modernise. Hospices tend to be somewhat secluded organisations in Britain, and external links and networks were mostly within the end-of-life care arena, with few referring to the wider volunteering and community fields. Volunteers were seen as an informal and symbolic 'link' to the local community, both in terms of their 'normalising' roles in the hospice, and as providing a two-way flow of information with the external environment where knowledge of hospice activities remains poor. The diversity of the community is not fully represented among hospice volunteers. A few hospices had deliberately tried to forge stronger interfaces with their localities, but these ventures were often controversial. The evidence suggests that there is substantial scope for hospices to develop the strategic aspects of volunteering through greater community engagement and involvement, and by increasing diversity and exploiting volunteers' 'boundary' position more systematically to educate, recruit and raise awareness. (RH)

ISSN: 09660410

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

Notes from the hospital bedside: reflections on researcher roles and responsibilities at the end of life in dementia; by Caroline Margaret Swarbrick, Elizabeth Sampson, John Keady.: Emerald, 2017, pp 201-211.

Quality in Ageing and Older Adults, vol 18, no 3, 2017, pp 201-211.

The authors explore some of the ethical and practical dilemmas faced by an experienced researcher in undertaking research with a person with dementia (whom they have called Amy). Amy died shortly after a

period of observation had ended and the family subsequently consented to the data being shared. This individual case study presentation was nested within a larger study conducted in England and Scotland between 2013 and 2014. The overall aim of the main study was to investigate how healthcare professionals and informal carers recognised, assessed and managed pain in patients living with dementia in a range of acute settings. The presented case study of Amy raises three critical reflection points: (i) Researcher providing care, i.e. the place and positioning of compassion in research observation; (ii) What do the stories mean? i.e. the reframing of Amy's words, gestures and behaviours as (end of) life review, potentially highlights unresolved personal conflicts and reflections on loss; and (iii) Communication is embodied, i.e. the need to move beyond the recording of words to represent lived experience and into more multi-sensory methods of data capture. Researcher guidance and training about end of life observations in dementia is presently absent in the literature, and this case study stimulates debate in a much overlooked area, including the role of ethics committees. (RH)

ISSN: 14717794

From : <http://www.emeraldinsight.com/loi/qaoa>

Perceived needs for support among care home staff providing end of life care for people with dementia: a qualitative study; by T Vandrevalla, K Samsi, C Rose, C Adenrale, C Barnes, J Manthorpe.: Wiley Blackwell, February 2017, pp 155-163.

International Journal of Geriatric Psychiatry, vol 32, no 2, February 2017, pp 155-163.

The aim of the current exploratory study was to investigate the impact on care home staff when working with people with dementia at the end of life and to explore how they cope with this aspect of their work. With UK policy encouraging death in the place of residence rather than hospital, more people with dementia are dying in care homes. A qualitative approach was employed: 20 care home staff working in five English care homes were interviewed. Thematic Analysis was used to analyse the data. Care home staff found the external demands on them and difficulties associated with interacting with people with dementia sometimes challenging, stressful and anxiety-provoking, particularly as residents approached end of life. Emotional aspects of caring for dying residents were sometimes heightened by close attachments with residents and their families. Staff were able to recognise these unmet needs and identified a need for further training and emotional support to manage these stressors. This study revealed rich and complex understandings of the practice dimensions of caring for people with dementia at the end of life and the impact these have on staff. There is a need to develop effective psychosocial interventions that focus on emotional support for care home staff. There will be challenges in providing this in employment settings that are generally low paid, low status, have high turnover and are reliant on temporary or migrant staff, where training is not rewarded, mandatory or culturally valued. (JL)

ISSN: 08856230

From : www.orangejournal.org

Trajectories of care home residents during the last month of life: the case of France; by Sophie Pennec, Joelle Gaymu, Elisabeth Morand (et al).: Cambridge University Press, February 2017, pp 325-351.

Ageing and Society, vol 37, no 2, February 2017, pp 325-351.

This paper examines some demographic and medical factors associated with the likelihood of residing in a care home during the last month of life for people aged 70 and over in France and, if so, of remaining in the care home throughout or being transferred to hospital. The data are from the Fin de vie en France (End of Life in France) survey undertaken in 2010. During the last month of life, very old people are more likely to be living in a care home but are not less likely to be transferred to hospital. Medical conditions and residential trajectories are closely related. People with dementia or mental disorders are more likely to live in a care home and, if so, to stay there until they die. Compared to care homes, a more technical and medication-based approach is taken in hospitals; and care home residents who are transferred to hospital more often receive medication, while those remaining in care homes more often receive support from a psychologist. In hospitals as in care homes, few older people had recourse to advance directives, and hospice programmes were not widespread. Promoting these two factors may help to increase the quality of end of life and facilitate an ethical approach to end-of-life care. (RH)

ISSN: 0144686X

From : journals.cambridge.org/aso

What is important at the end of life for people with dementia?: the views of people with dementia and their carers; by Sarah R Hill, Helen Mason, Marie Poole ... (et al).: Wiley, September 2017, pp 1037-1045.

International Journal of Geriatric Psychiatry, vol 32, no 9, September 2017, pp 1037-1045.

Approaching the end of life is often a time of vulnerability, particularly for people with dementia and their families where loss of capacity and the ability to communicate make assessment and shared decision-making difficult. Research has consistently shown that improvements in care and services are required to support better quality and more person-centred care for people with dementia towards and at the end of life. However the

views of people with dementia about what factors contribute to high-quality care at this time are a neglected area. The aim of this study was to identify aspects of end-of-life care for people with dementia that are most important to them and their carers. Q-methodology, a mixed method combining qualitative and quantitative techniques to study subjectivity, was used to identify the views of people with mild dementia, their family carers and bereaved carers on end-of-life care. 57 participants were included in the study. Four distinct views were identified: family involvement, living in the present, pragmatic expectations and autonomy and individuality. Some areas of consensus across all views included compassionate care, decisions being made by healthcare professionals and information availability when making decisions. Overall study findings revealed several different views on what is important about end-of-life care for people with dementia. So a 'one-size-fits-all' approach to care is unlikely to be most appropriate. Notwithstanding the differing viewpoints, these findings could provide a framework for service providers and commissioners for future care. (JL)

ISSN: 08856230

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

What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death; by Anna E Bone, Barbara Gomes, Simon N Etkind (et al). Palliative Medicine, 2017, 8 pp.

Population ageing represents a global challenge for future provision of health, social and end-of-life care. There has been a recent rise in the number of deaths at home (where most people would prefer to die) and a fall in deaths in hospital. However, given other new trends on place of death, where the rising number of deaths will occur in future years and the implications for health and social care will need to be examined. Using Office for National Statistics (ONS) data for England and Wales on place of registration for all deaths for 2004-2014, and predicted deaths for 2015-2040 from official population forecasts, the authors make projections on where people will die from 2015 to 2040 across all care settings. They applied age- and gender-specific proportions of deaths in hospital, care home, home, hospice and 'other' to numbers of expected future deaths. They estimate that annual deaths are projected to increase from 501,424 in 2014 (38.8% aged 85 years and over) to 635,814 in 2040 (53.6% aged 85 years and over). Between 2004 and 2014, the proportions of home and care home deaths both increased (18.3% to 22.9%, and 16.7% to 21.2% respectively), while hospital deaths declined (57.9% to 48.1%). If current trends continue, numbers of deaths in care homes and homes will increase by 108.1% and 88.6% respectively; and by 2040, the care home will be the most common place of death. However, if care home capacity does not expand and additional deaths occur in hospital, then hospital deaths will start to rise by 2023. Therefore, to sustain current trends, end-of-life care provision in care homes and the community needs to double by 2040. An infrastructure across care settings that supports rising annual deaths is urgently needed. Otherwise, hospital deaths will increase. (OFFPRINT.) (RH)

ISSN: 1477030X

From : <http://journals.sagepub.com/doi/pdf/10.1177/0269216317734435>

Why (some) older adults could benefit from making an advance decision to refuse treatment: how psychologists can help; by Celia Kitzinger, Sue Wilkinson.: British Psychological Society, January 2017, pp 42-45.

Psychology of Older People: The FPOP Bulletin, no 137, January 2017, pp 42-45.

Doing voluntary work with Advance Decisions Assistance (ADassistance.org.uk), the authors have worked with clients to help them to explain concerns about end-of-life care, and where appropriate, help them to write Advance Decisions to Refuse Treatment (ADRTs). The authors discuss pros and cons in general, and offer three examples of psychologists who had been involved in such discussions. All three were positive about the way in which ADRTs empowered patients, to give them "increased control" and feel that their wishes would be respected. However, many patients continue to be denied such opportunity, which might support a "good death". (RH)

ISSN: 20528914

From : <http://www.bps.org.uk/networks-and-communities/member-microsite/dcp-faculty-psychology-older-people-fpop>

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

Being accepted being me: understanding the end of life care needs for older LGBT people: a guide for health and social care professionals and carers; by Kathryn Almack, University of Nottingham; National Council for Palliative Care - NCP. London: National Council for Palliative Care, July 2016, 27 pp.

This guide aims to raise awareness of the end of life care needs of lesbian, gay, bisexual and trans (LGBT) older people, by providing information for health and social care staff and volunteers. It presents key facts on concerns about accessing health and social care services, and issues around disclosure of sexual orientation or gender identity. It includes points for discussion that could be used in training sessions. It is intended to complement the NCP publication and DVD, 'Open to all? Meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life'. Support from the Economic and Social Research Council (ESRC) is acknowledged. (RH)

Price: £5.00 (£2.00 to subscribers)

From : National Council for Palliative Care, 34-44 Britannia Street, London WC1X 9JG. Websites: www.ncpc.org.uk and www.dyingmatters.org.uk

Caring for a dying spouse at the end of life: 'it's one of the things you volunteer for when you get married': a qualitative study of the oldest carers' experiences; by Mary Turner, Claire King, Christine Milligan ... (et al.): Oxford University Press, May 2016, pp 421-426.

Age and Ageing, vol 45, no 3, May 2016, pp 421-426.

Older people aged 80 and over are increasingly providing end-of-life care to spouses at home and often do so for long periods of time, while also trying to manage their own illnesses and disabilities. Little of the research on older spousal carers has focused on the oldest carers - hence the needs of this particular population are not fully known. The objective of this study was to explore the experiences of the 'oldest carers' in caring for a dying spouse at home. Secondary analysis was undertaken on a subset of data from a larger qualitative interview study. This dataset comprised 17 interviews from participants aged 80 or over. Framework analysis methods were used, with items derived from the thematic analysis of the main study. The oldest carers in this subset demonstrated high levels of resilience and the ability to adapt to their caring role. Caring until death was accepted as an integral part of the commitment made to their partner as part of the 'wedding contract'. Carers felt they benefited from the support provided by family, friends and care services, however their own care needs were not always recognised by health and social care services. These findings underscore the complexity of the oldest carers' experiences and challenges in times of illness and end of life. Healthcare professionals should be alerted to the myriad ways caregiving is enacted in serious illness and seek opportunities for developing supportive interventions specifically for older carers. (JL)

ISSN: 00020729

From : www.ageing.oxfordjournals.org

Detained and dying: ethical issues surrounding end-of-life care in prison; by Meredith Stensland, Sara Sanders.: Taylor and Francis, July-September 2016, pp 259-276.

Journal of Social Work in End-of-Life and Palliative Care, vol 12, no 3, July-September 2016, pp 259-276.

Prisons are increasingly being called upon to provide end-of-life (EOL) care within the restrictive correctional environment. Several relatively recent phenomena have brought medical ethics to the forefront of prison EOL care - including ageing behind bars, a paradigm shift in prison culture, the increasing rate of in-prison deaths,

and the corresponding prison hospice movement. This article examines prominent ethical issues that emerge for prison staff who are tasked with providing care to terminally ill offenders by presenting three offender composite characters that exemplify dying offenders and emergent ethical issues surrounding their care. Identification and critical analysis of these ethical issues demonstrate the need for strong commitment to ethical practice and highlights specific issues for prisons to examine in their own EOL care practice. (JL)

ISSN: 15524256

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

Discussing end-of-life issues in nursing homes: a nationwide study in France; by Lucas Morin, Kristina Johnell, Lieve Van den Block, Regis Aubry.: Oxford University Press, May 2016, pp 395-402.

Age and Ageing, vol 45, no 3, May 2016, pp 395-402.

Discussing end-of-life issues with nursing home residents and their relatives is needed to ensure patient-centred care near the end of life. This study aimed to estimate the frequency of nursing home physicians discussing end-of-life issues with residents and their relatives and to investigate how discussing end-of-life issues was associated with care outcomes in the last month of life. This was a post-mortem cohort study in a nationwide, representative sample of 78 nursing home facilities in France. Residents who died from non-sudden causes between October 2013 and May 2014 in these facilities were included. End-of-life issues were discussed with at most 21.7% of the residents who died during the study period. In one-third of the situations, no discussion about end-of-life-related topics ever occurred, either with the resident or with the relatives. Older people with severe dementia were less likely to have discussed more than three of the six end-of-life topics investigated, compared with residents without dementia. In the last month of life, discussing more than three end-of-life issues with the residents or their relatives was significantly associated with reduced odds of dying in a hospital facility and with a higher likelihood of withdrawing potentially futile life-prolonging treatments. During the last months of life, discussions about end-of-life issues occurred with only a minority of nursing home decedents, although these discussions may improve end-of-life care outcomes. (JL)

ISSN: 00020729

From : www.ageing.oxfordjournals.org

End of life care: helping people to be cared for and die at home; by Alison Giles, Housing Learning and Improvement Network - Housing LIN. London: Housing Learning and Improvement Network - Housing LIN, February 2016, 14 pp (Practice briefing).

Public Health England commissioned the Housing LIN (Learning and Improvement Network) to produce this briefing. Drawing on the Housing LIN's knowledge of the sector, it looks at the importance of end of life care delivered at home. It considers the context, inequalities in end of life care, and examples of good or emerging practice. It is intended to be a practical guide for those working in mainstream and/or specialist housing, care and support, and public health to understand their respective roles, and how they may work with each other and with the wider health care system, to help people to have their end of life care wishes met.

From :

http://www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Practice_briefings/HLIN_Practice_Briefing_PHE_EndOfLife.pdf

End of life care service for people with dementia living in care homes in Walsall; by Rachael Dutton, Nicola Beeching, Sophie Meredith, Accord Group; Pathways 4 Life; Housing Learning and Improvement Network - Housing LIN. London: Housing Learning and Improvement Network - Housing LIN, May 2016, 7 pp (Case study, 123).

Published to coincide with Dying Matters Awareness Week 2016 (9-16 May), this case study focuses on an innovative end of life care service in Walsall initiated through collaboration with Pathways 4 Life (partnership between the Accord Group and Age UK Walsall) and St Giles Walsall Hospice. The core service consists of two community-based Dementia Support Workers (DSWs) who work in care homes across Walsall in order to provide expertise, insight and knowledge to further improve dementia and end of life care. The DSWs strive to empower care home staff, people with dementia and their families through development sessions, support and guidance, along with a strong partnership working ethic. The DSWs use a range of evidence-based tools, including the 'Namaste Care' approach, to advance a more holistic approach to dementia and care. This involves helping to create safe and relaxing spaces, and providing a broad spectrum of meaningful person-centred activities, some suitable for using with individuals, even at the very end stages of their lives. (RH)

From : Link to download:

<http://www.housinglin.org.uk/HousingRegions/WestMidlands/?&msg=0&parent=1022&child=10140>

Family caregiving and the site of care: four narratives about end-of-life care for individuals with dementia; by Anne P Glass.: Taylor and Francis, January-June 2016, pp 23-46.

Journal of Social Work in End-of-Life and Palliative Care, vol 12, nos 1-2, January-June 2016, pp 23-46.

Little is known about end-of-life care for individuals with Alzheimer's disease and other dementias. In this article four case studies are presented using data collected by qualitative interviews conducted with family caregivers who were closely involved with end-of-life care for relatives with dementia. The case studies are formatted in two pairs, with one reflecting two deaths occurring at home and the other pair representing two deaths in the nursing home. The cases reveal a range of end-of-life experiences, suggesting that there is not just one 'good' path. The extent of care needed, the responsiveness of the individual, the health of the caregiver(s), and the residence and support situations, can all intersect in a variety of ways that make no one scenario the answer for all. Although most people say they would prefer to die at home, in some situations the nursing home can be a satisfactory choice, particularly if hospice is involved. These narrative case studies give the reader insight into the variety of the end-of-life experiences and suggest the environment should be considered as part of the care provision. (JL)

ISSN: 15524256

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

Geographic variation of inpatient care costs at the end of life; by Claudia Geue, Olivia Wu, Alastair Leyland ... (et al.): Oxford University Press, May 2016, pp 376-381.

Age and Ageing, vol 45, no 3, May 2016, pp 376-381.

Costs incurred at the end of life are a main contributor to healthcare expenditure. Urban-rural inequalities in health outcomes have been demonstrated. Issues around geographical patterning of the association between time-to-death and expenditure remain under-researched. It is unknown whether differences in outcomes translate into differences in costs at the end of life. This study used a large representative sample of the Scottish population obtained from death records linked to acute inpatient care episodes. It performed retrospective analyses of costs and recorded the most frequent reasons for the last hospital admission. Using a two-part model, it estimated the probability of healthcare utilisation and costs for those patients who incurred positive costs. Effects of geography on costs were similar across diagnoses. There was not found to be a clear gradient for costs, which were lower in other urban areas compared with large urban areas. Patients from remote and very remote areas incurred higher costs than patients from large, urban areas. The main driver of increased costs was increased length of stay. These results provide evidence of additional costs associated with remote locations. If length of stay and costs are to be reduced, alternative care provision is required in rural areas. Lower costs in other urban areas compared with large urban areas may be due to urban centres incurring higher costs through case-mix and clinical practice. If inequalities are driven by hospital admission, for an end of life scenario, care delivered closer to home or home-based care seems intuitively attractive and potentially cost-saving. (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

Impacts of care-giving and sources of support: a comparison of end-of-life and non-end-of-life caregivers in Canada; by Allison M Williams, Li Wang, Peter Kitchen.: Wiley, March 2016, pp 214-224.

Health and Social Care in the Community, vol 24, no 2, March 2016, pp 214-224.

This is the second in a series of papers that deal with care-giving in Canada, as based on data available from Statistics Canada's General Social Survey ((GSS Cycle 21: 2007). The GSS includes three modules, where respondents were asked questions about the unpaid home care assistance that they had provided in the last 12 months to someone at end of life (EOL) or with either a long-term health condition or a physical limitation. This paper uniquely examines the caregiver supports employed by EOL caregivers when compared to non-EOL caregivers (short-term and long-term caregivers combined). It builds on the authors' first paper (Health and Social Care in the Community, vol 22, no 2, pp 187-196), which reviewed the differences between short-term, long-term and end-of-life caregivers. The objective of this paper was to investigate the link between the impact of the care-giving experience and the caregiver supports received, while also examining the differences in these across EOL and non-EOL caregivers. The authors use factor analysis and regression modelling to examine

differences between the two types of caregivers. The study revealed that with respect to socio-demographic characteristics, health outcomes and caregiver supports, EOL caregivers were consistently worse off. This suggests that although all non-EOL caregivers are experiencing negative impacts from their care-giving role, comparatively greater supports are needed for EOL caregivers. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

Live discharge from hospice and the grief experience of dementia caregivers; by Stephanie P Wladkowski.: Taylor and Francis, January-June 2016, pp 47-62.

Journal of Social Work in End-of-Life and Palliative Care, vol 12, nos 1-2, January-June 2016, pp 47-62.

When an individual has dementia, family members are involved in many care transitions in their roles as caregivers. One such transition is the 'live' discharge from hospice services. This occurs when an individual no longer meets eligibility criteria. This can be difficult for caregivers who have been anticipating an end to understand in the context of their grief process. This qualitative study explored the experiences of 24 caregivers of adults with dementia, including Alzheimer's disease, who experienced a 'live' discharge from hospice. Specifically, the experience of grief was examined. Results from this study highlight the complexity of caring for someone with a terminal disease and the grief experience in end-of-life care as caregivers struggle to understand the individual's terminal prognosis as temporary. This is further complicated for caregivers who must resume caregiving responsibilities or assume a new caregiving role after experiencing a loss of hospice services. Finally hospice social workers are well positioned to offer emotional and other concrete support to caregivers who experience a 'live' discharge. (JL)

ISSN: 15524256

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

The stigma experienced by terminally ill patients: evidence from a Portuguese ethnographic study; by Ana Patricia Hilario.: Taylor and Francis, October-December 2016, pp 331-347.

Journal of Social Work in End-of-Life and Palliative Care, vol 12, no 4, October-December 2016, pp 331-347.

The aim of this study was to offer an understanding of the ways in which terminally ill patients may face discrimination due to their visibly altered body. An ethnographic approach was adopted and fieldwork was conducted over 10 months in 2 in-patient hospice units in Portugal. Participant observation was complemented by 50 in-depth interviews with terminally ill patients, family members, and hospice staff. The stigma experienced by terminally ill patients derived mostly from the behaviour of peers, extended family members, and friends toward their visibly altered body. There was no evidence that these patients were discredited by their immediate family when they became visibly unwell, unlike what has been reported in previous studies. This finding could be related to the strong familial culture of Portuguese society. (RH)

ISSN: 15524256

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

We need to talk about caring: dealing with difficult conversations; by Anna Davies, Ciaran Osborne, Independent Age. London: Independent Age, July 2016, 41 pp.

In April 2016, Independent Age commissioned ComRes to survey a nationally representative sample of 2,066 people online, including 520 people aged 65+, to find out about their attitudes to and experiences of different conversation topics. This report presents findings on how and why families avoid talking about challenges they may face in older age. It covers: the types of conversations taking place; the family members that are hardest to talk to; the topics that are the most difficult to talk about; and the barriers to talking about ageing. In recommending what can be done to counter the barriers to difficult conversations, it suggests ways of: addressing the information problem; addressing unwillingness to consider residential care; and addressing the denial problem. It suggests tactics for initiating sensitive conversations, on which Independent Age has launched an online resource (independentage.org/difficult-conversations). (RH)

From : https://www.independentage.org/sites/default/files/2016-07/Difficult%20Conversations-%20Final%20for%20web%208_7_16_2016.pdf

What's the diagnosis?: organisational culture and palliative care delivery in residential aged care in New Zealand; by Rosemary Frey, Michal Boyd, Sue Foster (et al.): Wiley Blackwell, July 2016, pp 450-462.

Health and Social Care in the Community, vol 24, no 4, July 2016, pp 450-462.

Organisational culture has been shown to affect resident outcomes in residential aged care (RAC). This is particularly important, given the growing number of residents with high palliative care needs. The study described (conducted from January 2013 to March 2014) examined survey results from a convenience sample of 46 managers, alongside interviews with a purposively selected sample of 23 bereaved family members. The study aimed to explore the perceptions of organisational culture within New Zealand RAC facilities in one large

urban District Health Board. Results of the Organisational Culture Assessment Instrument (OCAI) completed by managers indicated a preference for a 'Clan' and the structured 'Hierarchy' culture. Bereaved family interviews emphasised both positive and negative aspects of communication, leadership and teamwork, and relationship with residents. Study results from both managers' OCAI survey scores and next of kin interviews indicate that while the RAC facilities are culturally oriented towards providing quality care for residents, they may face barriers to adopting organisational processes supportive of this goal. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

Your treatment and care: planning ahead for the LGBT community; by Compassion in Dying. London: Compassion in Dying, 2016, 30 pp.

Most people have some form of opinion about how they would like to be treated at the end of their lives, regardless of identity or background. For lesbian, gay, bisexual and transsexual (LGBT) people in particular, your identity might have an impact on the treatment and care you would like to receive. This guide aims to help you record your wishes to ensure they are respected if you cannot make a decision for yourself or tell people what you want. It provides an introduction to ways in which you can plan ahead for future treatment and care, by making a Lasting Power of Attorney for health and welfare (LPA), advance decision, or advance statement. It explains a person's rights under the Mental Capacity Act 2014, which applies in England and Wales. This guide was produced with assistance from Stonewall and Opening Doors London. (RH)

From : Compassion in Dying, 181 Oxford Street, London W1D 2JT. Website: www.compassionindying.org.uk

2015

The 2015 quality of death index: ranking palliative care across the world: a report by the Economist Intelligence Unit; commissioned by LIEN Foundation; by Sarah Murray, Economist Intelligence Unit - EIU. London: Economist Intelligence Unit, 2015, pp.

The Lien Foundation, a philanthropic organisation in Singapore commissioned the Economist Intelligence Unit (EIU) to devise a "Quality of Death" Index to rank 80 countries according to their provision of end-of-life care. The countries are evaluated using 20 quantitative and qualitative indicators across five categories: the palliative and healthcare environment, human resources, the affordability of care, the quality of care, and the level of community engagement. This report presents one or two case studies for each of these categories. To build the Index, the EIU used official data and existing research for each country, and also interviewed palliative care experts from around the world. As in the 2010 edition, this report finds that the UK has the best quality of death, because of the comprehensive integration of palliative care into the National Health Service (NHS) and a strong hospice movement; it also earns the best quality of care. Among other findings are that: less wealthy countries can still improve standards of palliative care rapidly, and that national policies are vital for extending access to palliative care. Quality of care depends on access to opioid analgesics and psychological support; and community efforts are important for raising awareness and encouraging conversations about death. (RH)

From : Download:

<http://www.economistinsights.com/sites/default/files/2015%20Quality%20of%20Death%20Index%20Oct%207%20FINAL.pdf>

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/>

Being mortal: medicine and what matters in the end; by Atul Gawande. London: Profile Books, in association with Wellcome Collection, 2015, 182 pp.

An American practising surgeon writes about the modern experience of mortality: what it is like to age, how medicines have changed things, and the inevitability of decline and death. He recalls interactions with patients he has encountered, and how things turned out. The ultimate goal should be for a good life, not a "good death". (RH)

Price: £9.99

Bridging the gap: strengthening relations between hospices and Muslims of Britain; by Sughra Ahmed, Naved Siddiqi, Woolf Institute; Hospice UK; Together for Short Lives. Cambridge: Woolf Institute, 2015, 45 pp.

Hospice UK and Together for Short Lives commissioned this report with the aim of learning how hospices and British Muslim communities can mutually strengthen engagement, so that hospices may provide the support needed by children and adults. Using research carried on over a 6-month period, the report looks at what is important to Muslims towards the end of life, and the barriers to engagement between hospices and Muslims in Britain. It also covers learning from national workshops, from the data, and from examples of best practice. Recommendations focus on three core areas. First, hospices and service providers should include information on religion and ethnicity in their records, to be used at registration of death and in preparing burial services. Second, hospices need to communicate and engage with local Muslim organisations, for example through community radio and television. Third, hospices, service providers and clinicians should seek specialist training programmes to better understand the "last journey" protocols and services. Joint training with mosques and Muslim burial services would also help in understanding what is needed from when a patient dies to the completion of burial rites of passage. (RH)

From : <https://www.hospiceuk.org/what-we-offer/publications?kwrd=Bridging%20the%20gap>

Care to learn: the introductory end of life care training programme: mentor's guidance book; by National Council for Palliative Care - NCPC.: National Council for Palliative Care - NCPC, 2015, 66 pp.

A 10-module programme comprising exercises and and answers, which is designed to help staff improve end of life care. It provides an introduction to good practice, and is designed to be flexible so that it can be tailored to each individual learner, organisation or locality. It is aimed at health care assistants and direct care staff across all settings. (RH)

Care to learn: the introductory end of life care training programme: student's book; by National Council for Palliative Care - NCPC.: National Council for Palliative Care - NCPC, 2015, 135 pp.

This 10-module programme comprises exercises and and answers, and is designed to help staff improve end of life care. It provides an introduction to good practice, and is designed to be flexible so that it can be tailored to each individual learner, organisation or locality. It is aimed at health care assistants and direct care staff across all settings. (RH)

Care-giving as a Canadian-Vietnamese tradition: it's like eating, you just do it; by Rhonda Donovan, Allison M Williams.: Wiley Blackwell, January 2015, pp 79-87.

Health and Social Care in the Community, vol 23, no 1, January 2015, pp 79-87.

This study examined how Vietnamese family caregivers (FCGs) perceive, manage and experience end-of-life care-giving for seriously ill family members. Using an instrumental case study design, this longitudinal qualitative research employed the use of cultural brokers/language interpreters to help ensure that the research was conducted in a culturally appropriate manner. Participants (n = 18) discussed their experiences of care-giving within the context of a traditional cultural framework, which was found to influence their motivations and approaches to care-giving, as well as their propensities towards the use of various supports and services. The study was carried out in southern Ontario, Canada, and participants were providing home-based care-giving in the community. Data were collected throughout 2010 and 2011. The ways in which care-giving was perceived and expressed are reflected in three themes: Natural: identity and care work; Intentional: whole-person care; and Intensive: standards, struggle and the context of care. This research confirms the need for culturally appropriate services and supports while illustrating that Vietnamese FCGs not only value, but are also likely to use healthcare and social services if they are language-accessible, built on trust and demonstrate respect for their values as individuals, regardless of culture. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

End-of-life care as a field of practice in the social work curriculum; by Susan Alsop Murty, Sara Sanders, Meredith Stensland.: Taylor & Francis, January-March 2015, pp 11-26.

Journal of Social Work in End-of-Life & Palliative Care, vol 11, no 1, January-March 2015, pp 11-26.

Attention to end-of-life care in social work education and practice is growing. With funding from the Project on Death in America, in 2001, the University of Iowa, School of Social Work developed and implemented an End-of-Life Field of Practice. Unlike a concentration, a Field of Practice is a set of integrated courses focused on one specific area of focus. This article describes the Field of Practice, the community-based partnerships, and the curriculum that serves as a basis for training the students enrolled in this area. Strategies for other social work programmes interested in developing a similar Field of Practice or speciality area in their MSW curricula are provided. These include faculty committed to the content area, comprehensive course offerings to encompass all aspects of end-of-life care, and field sites willing to help train students. (JL)

ISSN: 15524256

From : www.tandfonline.com

End-of-life co-residence of older parents and their sons in rural China; by Zhen Cong, Merrill Silverstein.: Cambridge University Press, September 2015, pp 331-341.

Canadian Journal on Aging, vol 34, no 3, September 2015, pp 331-341.

The authors examined how intergenerational exchanges with sons and daughters predicted older parents' likelihood of co-residing with a son prior to death in a rural area of China's Anhui Province. Their investigation drew on theories of contingent co-residence, modernisation, and social exchange. Co-residence was conceptualised as having practical and symbolic importance in rural Chinese culture. The sample included 470 older parents, reported as deceased during 2001-2009, and their posthumous informants. Logistic regression was used to assess intergenerational support and cohesion as predictors of co-residence with a son just prior to death. Older parents who provided instrumental support to, and received instrumental support from, sons and had better emotional relationships with sons were more likely than their counterparts to co-reside with a son at the end of life. Living with sons demonstrates filial piety for older parents at the end of life, but its realization is sensitive to intergenerational transactions. (RH)

ISSN: 07149808

From : journals.cambridge.org/cjg

Hospice enabled dementia care: the first steps: a guide to help hospices establish care for people with dementia, their families and carers; by Hospice UK. London: Hospice UK, March 2015, 51 pp.

Dementia care is an increasingly important strategic consideration for palliative and end of life care providers, including hospices. However, there is a degree of uncertainty about what such care could and should encompass. This guidance for hospices seeks to assure them they have much to offer people living with dementia and their families. It offers reasons why dementia care is an important consideration for palliative and end of life care providers in the future. It considers the degree to which the hospice sector has started to acknowledge the dementia challenge, and the principles underpinning high quality care for people with dementia, their families and carers. It uses examples of practice to illustrate the strengths of hospices: that their care is expert, flexible, timely, led by people's needs, and is integrated and provided in partnership with others. It provides checklists of what hospices must do to support people with dementia, their families and carers, for example an evidence-based approach to care and the care environment. It suggests resources to help hospices achieve high quality care for people with dementia, their families and carers. The development of this resource was funded by Hope for Home. (RH)

From : Download at: <http://www.hospiceuk.org/what-we-offer/clinical-and-care-support/hospice-enabled-dementia-care>

"I was ready to take him home": next-of-kin's accounts of loved one's death during hospice and palliative care discussions in veterans affairs medical centers; by Beverly Rosa Williams, F Amos Bailey, Hyunjin Noh ... (et al).: Taylor & Francis, January-March 2015, pp 50-73.

Journal of Social Work in End-of-Life & Palliative Care, vol 11, no 1, January-March 2015, pp 50-73.

This study explored next-of-kin's retrospective accounts of hospice and palliative care discussions for hospitalised veterans. In-depth, face-to-face interviews were used to generate narrative accounts of 78 next-of-kin's experience of their loved one's hospital care during the last days of the patient's life. One-third of participants reported taking part in a hospice or palliative care discussion during the patient's final hospitalisation. In over one-half of those cases, the patients died before discharge or transfer to hospice or palliative care was accomplished. Hospice and palliative care discussions in the hospital setting shaped family perceptions of the patients' care, directed family efforts in the days prior to death, and engendered anticipation of remaining quality time with the patient. Discussions about hospice or palliative care have meaning, emotional impact, practical effects and unintended consequences for next-of-kin. Social workers in hospital settings can play a critical role in supporting family members through the hospice and palliative care discussion process and facilitate timely care transitions. They also can attend to the psychosocial concerns of family members, particularly when death occurs prior to discharge to hospice or transfer to an inpatient palliative care service. (JL)

ISSN: 15524256

From : www.tandfonline.com

Lesbian, gay, bisexual and transgender people's attitudes to end-of-life decision-making and advance care planning; by Mark Hughes, Colleen Cartwright.: Wiley, 2015, pp 39-43.

Australasian Journal on Ageing, special issue, 2015, pp 39-43.

The present study aimed to examine lesbian, gay, bisexual and transgender (LGBT) people's attitudes to advance care planning (ACP) options and alternative decision-making at the end of life. 305 LGBT people completed an online or paper-based questionnaire, comprising fixed-choice questions and open-ended questions. Most respondents, particularly those identifying as female or transgender, preferred a partner to be their alternative decision-maker at the end of life should the need arise. 52% of respondents had spoken to this person about their wishes. Regarding legal options enabling end-of-life decision-making, 29% had an enduring power of attorney, 18% an enduring guardian and 12% an advance care directive. Despite the significance of ACP for promoting the rights of LGBT people at the end of life, the take-up of these options was nearly as low as for the general population. The potential for targeted strategies to increase the take-up of ACP is identified. (JL)

ISSN: 14406381

From : wileyonlinelibrary.com/journal/ajag

Living in the end times: a short course addressing end of life issues for older people in an English parish church setting; by Joanna Collicutt.: Emerald, 2015, pp 140-149.

Working with Older People, vol 19, no 3, 2015, pp 140-149.

The author reports on a pilot study that evaluated an innovative practice in a faith community context designed to help older people live well at the end of life and to prepare for death. Evaluation was by a simple audit of the intervention using a contemporaneous journal kept by the author, and a follow-up questionnaire completed by participants. Findings indicate a high degree of engagement by participants, the establishment of a high degree of group intimacy and trust, a high level of articulation of wisdom, the emergence of significant anxiety in some isolated cases, and the use made of tea and cake to manage the transition between the existentially demanding nature of the discussions and normal life. The outcome indicated very high levels of appreciation and increased confidence in relation to issues of death and dying. The findings of the pilot have been used to inform training of clergy in the principles of working in this area (e.g. in ways of managing group dynamics and anxiety, pacing, tuning in to archetypes, and the natural symbols that people use to talk about death and dying, self-care and supervision of the programme leader/facilitator). (RH)

ISSN: 13663666

From : www.emeraldgroupublishing.com/wwop.htm

National End of Life Care Intelligence Network: what we know now 2014; by National End of Life Care Intelligence Network, Public Health England. London: Public Health England, 2015, 55 pp.

Public Health England's National End of Life Care Intelligence Network (NEoLCIN) works with partner organisations to collect, analyse and present end of life care intelligence from a wide variety of sources. This report summarises the key findings of the Network and its partners during 2014 on five main themes: trends and attitudes to death, dying and society; care delivery and preferences for place of care; care in different settings; support for carers and families; and the end of life care workforce. Among the findings are that: the proportion of people dying at home or in care homes continues to increase; patients with an Electronic Palliative Care Co-ordination System (EPaCCS) record and those receiving palliative care services such as hospice at home, Gold Standards Framework or Macmillan services are more likely to die in the place of their preference; two in five people with dementia die in hospital, indicating that the trend towards increasing hospital deaths for people living with dementia has reversed. The factors most importance to people at the end of their life were: having pain and other symptoms managed effectively; being surrounded by loved ones; and being treated with dignity. More general practitioners (GPs) are having conversations with people about their end of life care wishes; but 25% still say they have never initiated such a conversation. (RH)

From : Download at: http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014

The national survey of bereaved people (VOICES) 2014: [Views of Informal Carers - Evaluation of Services]; by Office for National Statistics - ONS. [Newport]: Office for National Statistics - ONS, 09 July 2015, 30 pp (Statistical bulletin).

The national survey of bereaved people (VOICES, Views of Informal Carers - Evaluation of Services) collects information on bereaved peoples' views on the quality of care provided to a friend or relative in the last 3 months of life, for England. The survey has now been run for 4 years and was commissioned by the Department of Health in 2011 and 2012, and NHS England from 2013. VOICES data provides information to inform policy requirements, including the End of Life Care Strategy (published by the Department of Health, July 2008). This set out a commitment to promote high quality care for all adults at the end of life and stated that outcomes of end of life care would be monitored through surveys of bereaved relatives. It presents a range of information

regarding a person's quality of care, the dignity and respect afforded, coordination of care, relief of pain and overall level of care in the last three months of life. Also considered are: support for relatives, friends and carers; decision-making; and preferences and choices at the end of life. Links are provided to the previous surveys.
From : Download: http://www.ons.gov.uk/ons/dcp171778_409870.pdfContact: Helen Colvin, Life Events and Population Sources; Tel. +44 (0)1633 456431; Email: helen.r.colvin@ons.gsi.gov.uk

Social work practice with LGBT elders at end of life: developing practice evaluation and clinical skills through a cultural perspective; by Darren P Arthur.: Taylor and Francis, April-June 2015, pp 178-201.
Journal of Social Work in End-of-Life and Palliative Care, vol 11, no 2, April-June 2015, pp 178-201.
This article focuses on culturally sensitive clinical issues related to best practices with lesbian, gay, bisexual and transgender (LGBT) older dying patients at key points in the therapeutic relationship. Vital concepts, including practice evaluation and clinical skills are presented through a cultural and oncology lens. There is a paucity of LGBT research and literature as well as a shortfall of MSW graduate school education specific to social work palliative and end-of-life care (PELC) practice with LGBT older adults. The content of this article was designed to be adapted and used as an educational tool for institutions, agencies, graduate programmes, medical professions, social work and students. Learning the unique elements of LGBT cultural history and their implications on end-of-life (EOL) care can improve social work practice. (JL)
ISSN: 15524256
From : <http://tandfonline.com>

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

Spirituality and religion in end-of-life care ethics: the challenge of interfaith and cross-generational matters; by Holly Nelson-Becker, Amy L Ai, Faith P Hopp (et al).: Oxford University Press, January 2015, pp 104-119.
British Journal of Social Work, vol 45, no 1, January 2015, pp 104-119.
The complexity of illness and care needs at the end of life often include religious and spiritual issues. Religion and spirituality can be important coping mechanisms for meeting these challenges. However, although many people may want spirituality incorporated as a component of their care, spiritual needs are not always recognised or supported by the existing social care and medical systems. To address the need for more information on these issues, the authors present two social work cases that draw from our clinical experiences among patients with life-limiting disease conditions. Through these cases highlighting interfaith and cross-generational family issues, they identify different ways social workers may become involved in their interactions with patients' spiritual or religious concerns at the end of life. The authors conclude with suggestions for providing appropriate and culturally competent social and health care that promote aging in place for people with life-limiting illness conditions. (RH)

ISSN: 00453102

From : www.bjsw.oxfordjournals.org

Time for action: why end of life care needs to improve, and what we need to do next; by Simon Chapman, National Council for Palliative Care - NCPC.: National Council for Palliative Care, 2015, 11 pp.

Published in anticipation of the work of the Ambitions Partnership, a group of national organisations across the voluntary and statutory sectors that has come together to develop a new five-year vision and a fresh set of ambitions for end of life care over the coming Parliament. This short report elucidates four key themes which emerged from reports (published 2014 or 2015) by the Parliamentary and Health Ombudsman, the House of Commons Health Committee, and the Choice in End of Life Care Programme Board ('Choice Review') on end of life care. The key themes are: the need for leadership to give end of life care greater priority; an increase in well-coordinated community-based care; support for the workforce to enable them to deliver compassionate and competent care; and fairness and equality in the access and quality of end of life care. The National Council for Palliative Care (NCPC) calls for a review into how dying, death and bereavement are dealt with across government departments and public bodies. (NH/RH)

From : www.ncpc.org.uk

What's important to me: a review of choice in end of life care; by Choice in End of Life Care Programme Board. London: Choice in End of Life Care Programme Board, 2015, 72 pp.

The Choice in End of Life Care Programme Board was commissioned to provide advice to Government on improving the quality and experience of care for adults at the end of life, their carers and others who are important to them by expanding choice. This report identifies the issues people approaching the end of life are currently facing. It offers a blueprint for how greater choice in end of life care can be achieved. It looks at the context and challenge of providing end of life care. It summarises the findings of a consultation exercise with over 1,000 members of the public and professionals which looked at what kind of choices people wanted to make about their end of life care. The report makes evidence-based recommendations on what a 'national choice offer' should look like. Short case study examples are included throughout. The review also recommends that: 24/7 end of life care for people being cared for outside hospital should be in place across England by 2019; everyone in need of end of life care should have a named senior clinician responsible for their care and preferences and their own care coordinator; a clear Government policy to make access to social care for people at the end of life fast and free; and more honest and open communication about end of life issues, with better support for health and care professionals and increased awareness raising amongst the public. A final section provides advice to Government on the steps that will need to be put in place to deliver choice in end of life care. (RH)

From :

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf

2014

Advance care planning for Maori, Pacific and Asian people: the views of New Zealand healthcare professionals; by Rosemary Frey, Deborah Raphael, Gary Bellamy, Merryn Gott.: Wiley Blackwell, May 2014, pp 290-299.

Health and Social Care in the Community, vol 22, no 3, May 2014, pp 290-299.

Despite the benefits of advance care planning (ACP), international research has suggested that in pluralistic and multicultural societies such as New Zealand, significant differences exist in the uptake of ACP between European-based populations and other cultural groups (L M Crawley, 2005). This study explores the views of generalist palliative care providers in both the community and hospital settings regarding the barriers to ACP adoption as well as methods to increase knowledge about ACP among Maori, Pacific and Asian cultural groups within New Zealand society. Eleven individual interviews, two joint interviews, and three focus groups were conducted with health and social care professionals with a wide range of knowledge and experience in palliative care. Challenges were related to a number of issues based on culture, including family decision-making style, a need to 'do everything', and a reluctance to discuss issues surrounding dying and death. Suggestions to increase the knowledge of ACP included techniques to improve information access and the utilisation of shared norms and values to assist with discussions between Maori, Pacific and Asian health professionals and their patients and families or whanau. Findings indicate a need for more family- or whanau-centred models of ACP to be considered much earlier in the healthcare process and within the community setting.

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

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

Care of older adults: a strengths-based approach; by Wendy Moyle, Deborah Parker, Marguerite Bramble. Port Melbourne, VIC, Australia: Cambridge University Press, 2014, 213 pp.

This is a comprehensive introduction to aged care for the nursing profession in clinical practice, which encourages practice with a focus on individuals' potential and capacities rather than their limits. Theories of ageing are linked with the older individual's strengths. Divided into three parts, the book presents the topic from perspectives ranging from healthy ageing to chronic illness, frailty and end of life care. Case studies combine evidence-based knowledge with practical examples in a number of aged care settings, principally in Australia and New Zealand. (RH)

From : Cambridge University Press, Port Melbourne, VIC 3207, Australia. <http://www.cambridge.org>

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

Do people with dementia die at their preferred location of death?: A systematic literature review and narrative synthesis; by Vellingiri Badrakalimuthu, Stephen Barclay.: Oxford University Press, January 2014, pp 13-19.

Age and Ageing, vol 42, no 1, January 2014, pp 13-19.

Place of death is an important component of the quality of a person's death. This study undertook a systematic review and narrative synthesis of the literature concerning place of death of people with dementia and their preferences for location of death, and of the family carers and healthcare providers preferences about location of death for patients with dementia. Studies relying on death certificate data show that patients with dementia die more commonly in care homes than other locations, contrasting with prospective studies which show that death is more common in own residence and hospital. Age (older), gender (male), availability of hospital and nursing

home beds and enrolment in hospice, influence place of death. There is very limited evidence of patients, family carers and healthcare providers' views on preferred location of death for patients with dementia; and the only study included reported that family carers' views are more agreed to rather than patients' own views regarding place of death. This study on place of death raises exploratory questions on end-of-life care for patients with dementia, which has implications on health and social care policies related to dementia. (RH)

ISSN: 00020729

From : www.ageing.oxfordjournals.org

Duty to care?: supporting and involving unpaid carers of people at the end of life; by National Council for Palliative Care - NCPC. London: National Council for Palliative Care, 2014, 26 pp.

The Care Bill (2013) proposes that carers in England will have a right to an assessment by local authorities based on the appearance of need. This is a discussion document based on a conference held on 10th October 2013. It is also a teaching aid based on three scenarios discussed in workshops at the conference, which are also suited for use in training and development in the workplace. The scenarios are on these themes: culture, context and capability; capacity, collusion and choice; and conflict, confidentiality and crisis. The document was produced with supported by the Wellcome Trust and Dying Matters, in partnership with the Carers Trust, Marie Curie Cancer Care, Help the Hospices, Macmillan Cancer Support, and Sue Ryder. (RH)

Price: £5.00

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

Exploring resource use and associated costs in end-of-life care for older people with dementia in residential care homes; by Sarah Amador, Claire Goodman, Derek King ... (et al.): Wiley Blackwell, July 2014, pp 758-766.

International Journal of Geriatric Psychiatry, vol 29, no 7, July 2014, pp 758-766.

The goals of this study were to describe end-of-life care costs of older people with dementia (OPWD) residents in care homes (CHs) with no on-site nursing and evaluate the economic case for an intervention designed to improve end-of-life care for OPWD in CHs. Phase 1 tracked for a year, from March 2009, health services received by 133 OPWD in six residential CHs in the East of England. CH and resident characteristics were obtained through standardised assessment tools, interviews with CH managers and publicly available information from the independent regulator of social care services in England. Phase 2 used a modified Appreciative Inquiry intervention that ran for six months from January 2011, in three of the six CHs. Wilcoxon matched-pairs sign-rank tests were conducted to compare total cost and cost components during Phases 1 and 2 for those residents who had participated in both. Costs for each resident in Phase 1 were about £2800 per month, including service, accommodation and medication. Resource use was associated with resident characteristics. The intervention was perceived as having a positive impact on working relationships between CHs and visiting health care practitioners. Following the intervention total service costs fell by 43%. Hospital care costs fell by 88%. These results represent early work in an under-researched area of care. Appreciative Inquiry appears to improve and change working relationships with promising outcomes, but more research is needed to test these findings further with larger samples and more robust controls. (JL)

ISSN: 08856230

From : www.orangejournal.org

Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in the USA: perspectives of care managers on challenges and recommendations; by Jung Kwak, Eunjeong Ko, Betty J Kramer.: Wiley Blackwell, March 2014, pp 169-177.

Health and Social Care in the Community, vol 22, no 2, March 2014, pp 169-177.

This study examined care managers' perspectives on facilitating advance care planning (ACP) with ethnically diverse older people enrolled in Wisconsin Family Care, a care programme that coordinates medical and long-term care for frail, poor older people. Seven in-depth interviews and two focus groups were conducted with 24 lead supervisors and care managers of care management teams between July and August 2008; data were analysed with qualitative thematic analysis method. Participants identified four main sources of challenges: death and dying are taboo discussion topics; the dying process is beyond human control; family and others hold decision-making responsibility; and planning for death and dying is a foreign concept. Participants' recommendations coping with these challenges were to: develop trust with elders over time; cultivate cultural knowledge and sensitivity to respect value orientations; promote designating a healthcare proxy; recognise and educate families and community leaders as critical partners in ACP; and provide practical support as needed throughout the illness experience. These findings suggest important practice implications for care managers working with increasingly diverse cultural groups of older people at the end of life. (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>

Improving end of life care for people with advanced dementia; by Gaby Wills.: National Council for Palliative Care, March 2014, pp 16-18.

Inside Palliative Care, vol 27, March 2014, pp 16-18.

Looks at the work of Jewish Care (www.jewishcare.org), Britain's largest health and social care charity for the Jewish community, in providing end-of-life support for dementia sufferers. (JL)

ISSN: 17516129

From : www.ncpc.org.uk

LGBT people's knowledge of and preparedness to discuss end-of-life care planning options; by Mark Hughes, Colleen Cartwright.: Wiley Blackwell, September 2014, pp 545-552.

Health and Social Care in the Community, vol 22, no 5, September 2014, pp 545-552.

Despite the devastating impact of HIV/AIDS, end-of-life care planning among lesbian, gay, bisexual and transgender (LGBT) communities is relatively under-researched. This article reports findings of a survey of 305 LGBT people living in New South Wales, Australia, which examined their knowledge of and attitudes towards end-of-life care, specifically their preparedness to discuss any care plan with healthcare providers. The results highlight that while most respondents were aware of three of the four key end-of-life care planning options available in New South Wales - enduring powers of attorney, enduring guardians and person responsible (only a minority had heard of advance healthcare directives) - a much smaller number of people had actually taken up these options. Only a minority of respondents were able to identify correctly who had the legal right to make treatment decisions for a person who is unconscious following a car accident. A small proportion of people had discussed end-of-life care options with general practitioners or another main healthcare provider, and only in very few cases were these issues raised by the practitioners themselves. Those most likely to not feel comfortable discussing these issues with practitioners included younger people, those not fully open about their sexuality to family members, and transgender people and others who do not define their gender as male or female. The paper highlights the importance of education strategies to raise awareness of the end-of-life care planning options among LGBT people, as well as strategies for increasing health providers' preparedness to discuss these issues with LGBT patients. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

Living and dying: responsibility for end-of-life care in care homes without on-site nursing provision: a prospective study; by Melanie Handley, Claire Goodman, Katherine Froggatt (et al).: Wiley Blackwell, January 2014, pp 22-29.

Health and Social Care in the Community, vol 22, no 1, January 2014, pp 22-29.

Care homes with no on-site nursing provision rely on primary care services for access to medical, nursing and specialist services. This study describes the expectations and experiences of end-of-life care of older people resident in care homes, and how care home staff and the healthcare practitioners who visited the care home interpreted their role. A mixed-method design was used. The everyday experience of 121 residents from six care homes in the East of England were tracked; 63 residents, 30 care home staff with assorted roles and 19 National

Health Service staff from different disciplines were interviewed. The review of care home notes demonstrated that residents had a wide range of healthcare problems. Length of time in the care homes, functional ability or episodes of ill-health were not necessarily meaningful indicators to staff that a resident was about to die. General Practitioner (GP) and district nursing services provided a frequent but episodic service to individual residents. There were two recurring themes that affected how staff engaged with the process of advance care planning with residents: 'talking about dying', and 'integrating living and dying'. All participants stated that they were committed to providing end-of-life care and supporting residents to die in the care home, if wanted. However, the process was complicated by an ongoing lack of clarity about roles and responsibilities in providing end-of-life care; and doubts from care home and primary healthcare staff about their capacity to work together when residents' trajectories to death were unclear. The findings suggest that to support this population, there is a need for a pattern of working between health and care staff that can encourage review and discussion between multiple participants over sustained periods of time. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journal/hsc

Mobilising the workforce in end of life care; by Keri Thomas.: National Council for Palliative Care, March 2014, pp 19-21.

Inside Palliative Care, vol 27, March 2014, pp 19-21.

Describes and introduces the Gold Standards Framework (GSF), which gives outstanding training to all those providing end of life care to ensure better lives for people and recognised standards of care. GSF training programmes involve thousands of frontline staff in care homes, hospitals, primary care and beyond. (JL)

ISSN: 17516129

From : www.ncpc.org.uk

Residential aged care: the de facto hospice for New Zealand's older people; by Martin J Connolly, Joanna B Broad, Michal Boyd ... (et al).: Wiley, June 2014, pp 114-120.

Australasian Journal on Ageing, vol 33, no 2, June 2014, pp 114-120.

The present study aimed to describe short-term mortality among residential aged care (RAC) residents in Auckland, New Zealand. This was a census-type survey of all residential aged care facilities in the Auckland region, conducted during 2008. 861, or 12.6% of participants died within six months of taking the survey. Survival related to RAC length of stay before the survey: those resident for less than one month (subgroup 380) having 80.0% survival, 1-6 months 83.2% and six or more months 87.4%. In those admitted to private hospital from acute hospital (104 of the subgroup of 380), six-month mortality was 36.5%. Significant mortality predictors were: private hospital admission from acute hospital, unscheduled GP visit during the prior two weeks, personal care disability and acute hospital admission during the previous two years. These findings show that RAC mortality (especially post admission) is high. Training and resource in the sector should reflect this. (JL)

ISSN: 14406381

From : wileyonlinelibrary.com/journal/ajag

Towards a social model of end-of-life care; by Louise Brown, Tony Walter.: Oxford University Press, 2014, pp 2375-2390.

British Journal of Social Work, vol 44, no 8, 2014, pp 2375-2390.

Challenges the social work profession to consider whether the hospice and palliative care model of end-of-life care needs to be rethought and argues for the development of a more community engagement model.

ISSN: 00453102

From : www.bjsw.oxfordjournals.org

Transitions in later life: a review of the challenges and opportunities for policy development; by Guy Kerr Robertson.: Emerald, 2014, pp 186-196.

Working with Older People, vol 18, no 4, 2014, pp 186-196.

This paper outlines an approach to understanding later life issues through the conceptual framework of "transitions". The paper draws on a wide-ranging review of the literature, supported by two workshop sessions involving key stakeholders and experts in the field. It analyses the efficacy or otherwise of the support available for people undergoing these major transitions: retirement; becoming a carer; acquiring a health condition; and preparing for end of life. It comments on key issues relating to these transitions: resilience, personal capabilities, and community support. The study derives its data largely from a review of published literature, and therefore lacks the input from older people themselves. The analysis provides guidance to policy makers and others interested in the later life agenda with well-researched recommendations for change. There are significant social

implications in the recommendations and the opportunity for the experiences in later life to be framed in a transitions paradigm. (RH)

ISSN: 13663666

From : www.emeraldinsight.com/wwop.htm

Understanding integrated working between arts and care settings: an analytical framework for planning and research; by Michael Clark.: Emerald, 2014, pp 241-252.

Journal of Integrated Care, vol 22, no 5/6, 2014, pp 241-252.

The purpose of this paper was to discuss integrated working between the arts and those in care settings. This was a conceptual discussion drawing upon insights from relevant literature and a case study analysis of an integration project between a hospice service, an art gallery and an artist. The project, known as Life:Still, highlighted some points about a lack of conceptual frameworks to help locate the purpose of diverse arts and care projects. There is scope for much confusion about the nature and purpose of such integration projects without a clear framework for articulating the aims of individual integration endeavours and their place in relation to other arts and care work. This paper develops a framework and a clear understanding about the different kinds and goals of integrated working between arts and care settings to help with future practical and research projects. In particular the case study highlights key themes from which generalisation to other services will require interpretation for particular contexts. The ideas present a helpful approach to articulating the goals of individual projects and understanding the place of projects in relation to other arts and care initiatives. There is much scope for better integrated working between arts and care settings to achieve better outcomes for users of care services, and the ideas presented here should help to better organise and evaluate such developments. This is the first paper to set out the framework presented to help with better integrated working between arts and care settings. (JL)

ISSN: 14769018

From : www.emeraldinsight.com/jica.htm

2013

10 questions to ensure good end of life care in your area; by Simon Chapman, Dying Matters Coalition; National Council for Palliative Care - NCPC; Marie Curie Cancer Care. London: National Council for Palliative Care; Marie Curie Cancer Care, 2013, 18 pp.

This document is published with the implementation of health and social care reforms in April 2013 and how they are made to work for the benefit of people approaching the end of life and the people caring for them. It asks why each of the ten questions is important, what else to ask, and suggests further information sources. Local provision on end of life care is considered with questions about: where people are dying and where they are being cared for before they die; the quality of care received; the systems that identify people approaching the end of life and how plans about care can be coordinated; services "at any time of day and night" to enable people to be cared for in the place they want to be; support for carers, including into bereavement; services that are genuinely available and accessible to all; training in end of life care for staff; end of life care as a priority, including leadership and accountability; raising public awareness about death, dying and bereavement; and involving local people and those with personal experience in shaping and evaluating services. (RH)

Price: £10.00

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

Anticipatory grief therapy for older persons nearing the end of life; by Joanna O Y Cheng, Raymond S K Lo, Jean Woo.: Future Medicine, February 2013, pp 103-114.

Aging Health, vol 9, no 1, February 2013, pp 103-114.

Ageing brings about multiple and accumulating losses over a long trajectory of illness with deterioration in overall functioning with secondary losses in social and existential domains. The reality of anticipatory grief (AG) in older patients facing the end of life is easily overlooked with little provision of psychosocial support, especially for those ageing in institutions without integrated palliative care services. This article discusses the challenges that AG poses for the older patients, as well as the desired therapeutic outcomes through using this approach. The evidence base for AG therapy has been limited. Beneficial therapeutic approaches for AG-related constructs are reviewed, with recommendations to design interventions that target the AG of older patients facing different advanced conditions. AG interventions successfully implemented in the end-of-life care pathway may ensure optimal palliative care for the family. (JL)

ISSN: 1745509X

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

Better together?: evaluation of the welfare benefits advice service partnership project between Isabel Hospice and East Herts Citizens Advice Service.: National Council for Palliative Care, July 2013, pp 20-21.

Inside Palliative Care, vol 24, July 2013, pp 20-21.

Since 2010 Isabel Hospice and East Herts Citizens Advice Service have worked in partnership to deliver a welfare benefits and advice service to the patients of Isabel Hospice, their families and carers. The objective of the service is to provide advice to patients and their families who may suffer financial hardship due to their life-limiting illness to claim the welfare benefits to which they are entitled, thereby alleviating some of the anxiety caused by their financial situation. (JL)

ISSN: 17516129

From : www.ncpc.org.uk

Death and dying in residential care: a matter of concern; by Randall Smith.: Emerald, 2013, pp 205-217.

Quality in Ageing and Older Adults, vol 14 no 3, 2013, pp 205-217.

The author traces the history of official policy on the regulation of care homes in respect of end of life care, also what is required to support care home staff in relation to dying residents and their relatives. A central concern is to argue for the open recognition that care homes now cater primarily for frail people towards the end of their lives. Good end-of-life care and a good death could become a positive "selling point". The author concludes that the system of regulation has broadly failed to address a good death or good end of life care in a residential home. Death talk should no longer need to be avoided in care homes. The research suggests that appropriate support for care home staff in relation to dying residents needs careful identification and investment. A cultural shift is required. Following a review of policy documents on regulation and standards of care in residential homes and a subsequent review of the research literature on death and dying in care homes, the paper illuminates the contrast between the ambitious aims in policy documents with very varied practice in everyday care of frail residents. The recent systems of regulation have broadly failed to address a good death or good end-of-life care in residential homes. Open acknowledgement of death and dying should not be avoided in care homes. Appropriate support for care home staff in relation to dying residents needs careful identification and investment. The focus of this paper is to contrast official policy with everyday practice. Whilst policy documents suggest recognition of the importance of dignity and respect from dying residents, the research literature indicates great variation in the practice of everyday care. (RH)

ISSN: 14717794

From : www.emeraldinsight.com/qaoa.htm

Decriminalising an expected death in the home: a social work response; by Margaret E Hughes.: Oxford University Press, March 2013, pp 282-297.

British Journal of Social Work, vol 43, no 2, March 2013, pp 282-297.

An issue yet to be examined in the social work research literature concerns an expected death at home and the experiences of informal carers being subjected to a police investigation following a request for help. While research in this area is scant, sufficient mention of unnecessary police involvement is made in the palliative care literature to show that incidents like these have occurred throughout Australia, America, Canada and the UK. This article examines the Australian context, analysing the practice of reporting deaths to the police in instances where a doctor is not immediately available to attend the home to certify the death of a person diagnosed with a terminal condition. Personal accounts from three research participants derived from a subset of data analysed for a larger qualitative study are used as empirical evidence to illuminate the impact of unnecessary police involvement. Using critical social work theory to examine unnecessary end-of-life intervention, this paper argues for greater social work activity within the context of home-based palliative care, so that the rights of informal carers to relevant information is improved, and expected deaths at home are no longer considered crime scenes warranting police investigation. (JL)

ISSN: 00453102

From : www.bjsw.oxfordjournals.org

Dementia: from difficult conversations to better outcomes; by Beth Lloyd-Williams.: National Council for Palliative Care, July 2013, pp 14-15.

Inside Palliative Care, vol 24, July 2013, pp 14-15.

Briefly outlines details of a project run by the National Council of Palliative Care (NCPC) in partnership with North Hampshire Clinical Commissioning Group (CCG) providing training for GPs in holding difficult conversations around end-of-life care and advance care planning with dementia sufferers and their carers. (JL)

ISSN: 17516129

From : www.ncpc.org.uk

Developing emotional competence of social workers of end-of-life and bereavement care; by Amy Y M Chow.: Oxford University Press, March 2013, pp 373-393.

British Journal of Social Work, vol 43, no 2, March 2013, pp 373-393.

Facing an excessive number of deaths and the intense emotions of bereaved family members, social workers who work with dying and bereaved persons are confronted with exceptional emotional challenges. Based on two models of death anxiety, an education programme was developed with different experiential exercises with the aim of enhancing the emotional competence of social workers in Hong Kong. Through working with regrets and meaningfulness, the programme aims at reducing personal death anxiety, hopefully reducing the distress and non-empathetic responses of the social workers. An effectiveness study with 385 participants was carried out. Data were collected at three time points (pre, post and follow-up) to capture the changes over time. The programme is considered successful as, according to the statistics gathered, the major outcomes of work comfort and competence level improved. Statistically significant changes across time were found in death anxiety and meaningfulness. Moreover, correlations were found between death anxiety and competence and comfort level. It is anticipated that the programme can be used and tested by social work educators and other helping professionals in other parts of the world. (JL)

ISSN: 00453102

From : www.bjsw.oxfordjournals.org

Development and evaluation of the REACH (Recognise End of life And Care Holistically) out in Dementia toolkit; by Jan M Potter, Ramesh Fernando, Nancy Humpel.: Wiley Blackwell, December 2013, pp 241-246.

Australasian Journal on Ageing, vol 32, no 4, December 2013, pp 241-246.

The purpose of the study was to identify evidence based signs and symptoms indicative of end stage dementia, and develop the REACH (Recognise End of Life and Care Holistically) toolkit as an aid for staff to consider a palliative approach. A systematic literature review was conducted of policy, position documents, guidelines and publications from 1988 to 2011. Inclusion criteria were any report or article identifying the signs and symptoms of end stage dementia which were associated with increased mortality and morbidity. Eight signs and symptoms associated with worsening function and increased mortality were identified. These were: dependence on others for all activities of daily living; communication difficulties; eating and/or feeding difficulties; deterioration in mobility and posture; development of contractures because of muscle rigidity; persistent confusion; recurrent infections; and inability to recognise familiar objects or family and friends. All these were incorporated into a toolkit which was reviewed by experienced clinicians. The toolkit was then trialled in six aged care facilities (ACFs). As a result 182 residents with dementia were identified as being at the end stage. Overall study findings of the study showed that use of the toolkit improved the recognition of end stage dementia among staff in ACFs. (JL)

ISSN: 14406381

From : wileyonlinelibrary.com/journal/ajag

End of life care and South Asian kidney patients; by Neerja Jain.: National Council for Palliative Care, July 2013, pp 18-19.

Inside Palliative Care, vol 24, July 2013, pp 18-19.

Briefly looks at reasons for the low take-up of palliative and end-of-life care services among the Black and Asian community in Britain, particularly those who are dying from kidney disease. (JL)

ISSN: 17516129

From : www.ncpc.org.uk

End-of-life care in a rehabilitation centre for older people in Australia; by Heather Tan ... (et al): Wiley Blackwell, September 2013, pp 184-187.

Australasian Journal on Ageing, vol 332, no 3, September 2013, pp 184-187.

The purpose of this study was to investigate processes at the end of life for patients who died in a subacute evaluation and management facility for older people. A retrospective chart audit for 55 patients who had died in the previous two years was undertaken, recording a number of significant variables. Despite diagnosis of comorbid medical conditions, most participants were admitted for improved functioning or assessment for alternative accommodation. Consistent with this focus, the key contact person was most often an allied health team member. Not For Resuscitation order and/or power of attorney documents on admission were uncommon, as were referrals to palliative care specialist staff, although an end-of-life discussion was recorded (90%) and often included as a new goal of care (71%). Factors likely to improve end-of-life care included advance care planning, earlier recognition of short prognosis and staff education. (JL)

ISSN: 14406381

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

Gentle dusk - future matters: a volunteer-led programme empowering communities in end of life care planning.: National Council for Palliative Care, December 2013, pp 16-17.

Inside Palliative Care, vol 26, December 2013, pp 16-17.

Gentle Dusk _ Future Matters (www.gentledusk.org.uk) is an agency run by trained volunteers offering an outreach service to local communities to raise awareness of the importance of end-of-life care planning. (JL)

ISSN: 17516129

From : www.ncpc.org.uk

Hospice: putting the heart back into dementia care; by Michael Tapley, Ann Regan, David Jolley.: Hawker Publications, September/October 2013, pp 14-15.

Journal of Dementia Care, vol 21, no 5, September/October 2013, pp 14-15.

The authors report on the action taken at Willow Wood Hospice in Ashton under Lyne to help meet the end of life care needs of people with dementia. (RH)

ISSN: 13518372

From : www.careinfo.org

Improving the end-of-life for people with dementia living in a care home: an intervention study; by Gill Livingston ... (et al).: Cambridge University Press, November 2013, pp 1849-1858.

International Psychogeriatrics, vol 25, no 11, November 2013, pp 1849-1858.

One in three adults, most of whom are living in a care home at the time, dies with dementia. Their end-of-life is often in hospital, where they may experience uncomfortable interventions without known benefit and die rapidly with uncontrolled pain and comfort needs. This study aimed to improve end-of-life care for people with dementia in a care home by increasing the number and implementation of advanced care wishes. The study recruited staff, residents with dementia, and their relatives from a 120-bed nursing home in London. The intervention was a ten-session manualised, interactive staff training programme. The study compared advance care wishes documentation and implementation, place of death for residents who died, and themes from staff and family carers' after-death interviews pre- and post-intervention. Post-intervention there were significant increases in documented advance care wishes arising from residents' and relatives' discussions with staff about end-of-life. These included do not resuscitate orders and dying in the care homes as opposed to hospital. Bereaved relatives' overall satisfaction increased from 7.5 pre-intervention to 9.1 post-intervention. Relatives reported increased consultation and satisfaction about decisions. Staff members were more confident about end-of-life planning and implementing advanced wishes. This small non-randomised study is the first end-of-life care in dementia intervention to report an increase in family satisfaction with a reduction in hospital deaths. This is promising but requires further evaluation in diverse care homes. (JL)

ISSN: 10416102

From : journals.cambridge.org/ipg

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

A longitudinal study of end-of-life preferences of terminally-ill people who live alone; by Samar M Aoun, Kim Skett.: Wiley Blackwell, September 2013, pp 530-535.

Health and Social Care in the Community, vol 21, no 5, September 2013, pp 530-535.

As a home death seems to be the perceived ideal, terminally ill people who live alone are at a disadvantage in terms of their place of care and death, and little is known about their end-of-life preferences. This study aimed at eliciting patient preferences for their place of care and death longitudinally at two points during their illness trajectory, and reporting on the extent they were able to achieve their place of choice or congruence between preferred and actual place of death. A questionnaire was administered by a researcher in the patients' homes during two visits, 6-12 weeks apart depending on patient prognosis. Forty-three patients of Silver Chain Hospice Care Service in Western Australia participated during 2009-2010. The results indicate that preferences were in favour of either a home or hospice death, with more preferring home as a place of death rather than a place of care. However, overall congruence between preferred and actual place of death was between 53% and 41% dependent on whether it was based on first or second visit preferences respectively. This is the first longitudinal study to elicit the end-of-life preferences of terminally ill people who live alone. As home may not be the preferred location for dying for many patients (nearly half of the patients in this study), ability to die in the place of choice needs to be looked at as a possible indicator of meeting patient needs or as a quality measure in end-of-life care. (RH)

ISSN: 09660410

From : wileyonlinelibrary.com/journals/hsc

More care, less pathway: a review of the Liverpool Care Pathway; by Julia Neuberger (chair), Independent Review of the Liverpool Care Pathway. London: Department of Health, July 2013, 63 pp.

Developed from a model of care successfully used in hospices, the Liverpool Care Pathway for the Dying Patient (LCP) is a generic approach to care for the dying, intended to ensure that uniformly good care is given to everyone thought to be dying within hours or within two or three days, whether they are in hospitals, nursing homes, or in their own homes. Following criticism of the LCP in the media and elsewhere, Norman Lamb, Minister of State for Care Support, asked Baroness Julia Neuberger to chair a panel to review of the use and experience of the LCP in England, to be kept independent of Government and the NHS. This report presents the Independent Review's findings and recommendations in respect of: diagnosis of dying; decision-making; consent; involvement in the care plan; hydration and nutrition; sedation and pain management. Other items, including 'Rapid evidence review: pathways focused on the dying phase in end of life care and their key components' are available on main link (see: <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>). (RH)

From : Download:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

Namaste care: the next step in making our hospitals dementia friendly?.: National Council for Palliative Care, July 2013, pp 26-27.

Inside Palliative Care, vol 24, July 2013, pp 26-27.

Namaste Care is a sensory based programme based at King's College Hospital, London, integrating nursing care with meaningful activities to provide peaceful and relaxing experiences for patients with advanced dementia. 'Namaste' is a hindu greeting which literally means to honour the spirit within. (JL)

ISSN: 17516129

From : www.ncpc.org.uk

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

Professional and educational needs of hospice and palliative care social workers; by Sherri M Weisenfluh, Ellen L Csikai.: Taylor and Francis, January-March 2013, pp 58-73.

Journal of Social Work in End-of-Life and Palliative Care, vol 9, no 1, January-March 2013, pp 58-73.

In recent years the number of patients and families served by hospices and palliative care services has increased. These services have also been subject to increasing regulation by government. In order to stay up-to-date in this ever-changing environment and to continue to provide effective interventions social workers must stay engaged in the professional community and continuing education. In this quantitative study 1,169 practising hospice and palliative care social workers provided information about their practice activities and agency characteristics, professional affiliations and certification, and ongoing educational needs. About one-half of respondents carried a caseload of 21-50 and were mostly engaged in communicating the psychosocial needs of the patient and family to other members of the team and assessing for grief and bereavement issues. The most important educational needs pertained to the psychological and social needs of patients and families and psychosocial interventions. Although many were aware of the joint NASW-NHPCO social work hospice speciality certification few held this certification yet. The authors conclude that the results of this survey could be used in the design of continuing education programmes and advocacy for policy change. (JL)

ISSN: 15524256

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

The public's viewpoint on the right to hastened death in Alberta, Canada: findings from a population survey study; by Donna M Wilson, Stephen Birch, Rod MacLeod ... (et al): Wiley, March 2013, pp 200-208.

Health and Social Care in the Community, vol 21, no 2, March 2013, pp 200-208.

A research study was conducted to determine public opinion in Alberta, Canada, on the controversial topic of death hastening. Questions on the right to hastened death, end-of-life plans and end-of-life experiences were included in the Population Research Laboratory's annual 2010 health-care telephone survey, with 1,203 adults providing results relatively representative of Albertans. Of all 1,203, 72.6% said yes to the question: 'Should dying adults be able to request and get help from others to end their life early, in other words, this is a request for assisted suicide'? Among all who provided an answer, 36.8% indicated 'yes, every competent adult should have this right' and 40.6% indicated 'yes, but it should be allowed only in certain cases or situations'. Over 50% of respondents in all but one socio-demographic population sub-group (Religious-other) were supportive of the right to hastened death. However, multinomial regression analysis revealed that the experiences of deciding to euthanise a pet/animal and developing or planning to develop an advance directive predicted support, while self-reported religiosity predicted non-support. Finding majority public support for death hastening suggests that legalisation could potentially occur in the future. However such a policy should first require a careful consideration of the model of assisted suicide or euthanasia that best protects people who are highly vulnerable to despair and suffering near the end of life. (JL)

ISSN: 09660410

From : www.wileyonlinelibrary.com/journals/hsc

Quality of dying of nursing home residents with dementia as judged by relatives; by Nicole van Uden ... (et al): Cambridge University Press, October 2013, pp 1697-1707.

International Psychogeriatrics, vol 25, no 10, October 2013, pp 1697-1707.

Providing good quality care for the growing number of patients with dementia is a major challenge. There is little international comparative research on how people with dementia die in nursing homes. This study compared the relative's judgment on quality of care at the end of life and quality of dying of nursing home residents with dementia in Belgium and the Netherlands. This was a Belgian cross-sectional retrospective study (2010) combined with a prospective and retrospective study from the Netherlands (January 2007-July 2011). Relatives of deceased residents of 69 Belgian and 34 Dutch nursing homes were asked to complete questionnaires. The study included 190 and 337 deceased nursing home residents with dementia in Belgium and the Netherlands respectively. Of all identified deceased nursing home residents with dementia, respectively 53.2% and 74.8% of their relatives in Belgium and the Netherlands responded. Comfort while dying was rated better for Dutch nursing home residents than for Belgian nursing homes residents. No differences were found between countries regarding satisfaction with care or symptom frequency in the last month of life. Although nursing home structures differ between Belgium and the Netherlands, the quality of care in the last month of life for residents with dementia is similar according to their relatives. However, Dutch residents experience less

discomfort while dying. The results suggest room for improved symptom management in both countries and particularly in the dying phase in Belgium. (JL)

ISSN: 10416102

From : journals.cambridge.org/ipg

Reaching the whole community?: end of life care for all who need it; by National Council for Palliative Care - NCPC. London: National Council for Palliative Care, 2013, 19 pp.

This report sets out the emerging priorities and themes highlighted at a national conference held on 18th April 2013, organised by the National Council for Palliative Care (NCPC) and the Dying Matters coalition. It provides some key facts about current access to end of life care; and considers those who might be labelled "hard to reach" (minority ethnic communities, and lesbian, gay, bisexual and transgender, or LGBT, for example). It concludes with some good practice examples, also lists of discussion documents and websites. (RH)

ISBN: 1898915997

Price: £5.00

From : National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.

www.ncpc.org.uk

The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review; by Oliver R Herber, Bridget M Johnston.: Wiley Blackwell, May 2013, pp 225-235.

Health and Social Care in the Community, vol 21, no 3, May 2013, pp 225-235.

Despite the widespread use of Health Care Support Workers (HCSWs) in providing palliative and end-of-life care, there is little information available about their contributions towards supporting patients who want to be cared for and/or die at home. Between January and April 2011, a systematic review was conducted to address two questions: (i) What particular tasks/roles do HCSWs perform when caring for people at the end of life and their families to comply with their desire to remain at home?; (ii) What are the challenges and supporting factors that influence HCSWs' ability to provide palliative and end-of-life care in the community? A search was carried out for papers published from 1990 to April 2011. In total, 1,695 papers were identified, ten of which met the eligibility criteria of the study. After the methodological quality of the studies was appraised, nine papers were included in the review. The findings indicated that HCSWs invest a great deal of their time on emotional and social support as well as on assisting in the provision of personal care. They are also involved in providing care for the dying, respite care for family members and offer domestic support. Although it is important to acknowledge the many positive aspects that HCSWs provide, the findings suggest three challenges in the HCSWs role: emotional attachment, role ambiguity and inadequate training. Support factors such as informal peer grief-support groups, sense of cohesiveness among HCSWs and task orientation enabled HCSWs to overcome these challenges. To conclude, induction and training programmes, a defined period of preceptorship, appropriate support, supervision and clearly defined role boundaries may be helpful in reducing the challenges identified in HCSWs' roles. (JL)

ISSN: 09660410

From : www.wileyonlinelibrary.com/journals/hsc

Ways and means; by Ally Paget, Claudia Wood, Demos. London: Demos, 2013, 150 pp.

The quality of care experienced at the end of life is frequently characterised by delays, a lack of information and insufficient consideration given to the wishes of patient and family to achieve "a good death". This report was developed by Demos for Sue Ryder, to explore the quality of the patient experience of end of life care services, and what can be done to improve this journey through the different fields of health and social care from the patient's perspective. Early diagnosis, a high level of personalisation and ongoing seamless support are crucial to delivering a good service and reducing inequalities in end of life care. (Note: On title page: "People's final journey must be one of their choosing ...") (RH)

From : Download: http://www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165

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 difference 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 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

Where do I go from here?: a cultural perspective on challenges to the use of hospice services; by Rosemary Frey, Merryn Gott, Deborah Raphael (et al): Wiley Blackwell, September 2013, pp 519-529.

Health and Social Care in the Community, vol 21, no 5, September 2013, pp 519-529.

Do hospice services as shaped by a western perspective adequately fulfil the needs of persons from non-Western cultures? Based on a Western view of palliative care, the vision outlined in the New Zealand Palliative Care Strategy (2001) is to deliver palliative care services, including hospice services, to all patients and their families requiring them in the context of an increasingly pluralistic and multicultural society. It is predicted that over the next two decades the proportion of people in New Zealand identifying as Maori, Pacific and Asian will dramatically increase. Ministry of Health information provided through a GAP analysis identified hospices as facing access-to-care pressures for Maori, Pacific and Asian patients. It is therefore critical to identify the challenges to hospice service access for Maori, Asian and Pacific patients. This project involved qualitative interviews with 37 cancer patients (Maori, Pacific and Asian self-identified ethnicities), whanau/family and bereaved whanua/family, as well as 15 health professionals (e.g. referring GPs, oncologists, allied health professionals) within one District Health Board. Patients and their families included both those who utilised hospice services, as well as those non-users of hospice services identified by a health professional as having palliative care needs. Challenges to hospice service utilisation reported included a lack of awareness in the communities of available services, as well as continuing misconceptions concerning the nature of hospice services. Language barriers were particularly reported for Asian patients and their families. Issues concerning the ethnic representativeness of the hospice services staff were raised. The findings highlight the importance of patient and family knowledge of hospice care for utilisation of services. This information can be used for future planning to enable hospices to both provide high quality evidence-based palliative care services for patients and families, and to provide consultative services to primary healthcare providers in the community. (RH)

ISSN: 09660410

From : [wileyonlinelibrary.com/journals/hsc](http://www.wileyonlinelibrary.com/journals/hsc)

Who cares? Support for carers of people approaching the end of life: a discussion based on a conference held on 6th November 2012; by National Council for Palliative Care - NCPC. London: National Council for Palliative Care - NCPC, 2013, 19 pp.

There are at least half a million people currently caring for someone at the end of life. Carers are often an overlooked part of end of life care, who face difficulties in coping with complex needs and in coordinating care. In November 2012, the National Council for Palliative Care (NCPC), Carers Trust and partners held their first ever national conference focusing on the needs of carers of those approaching the end of life. This report explores five themes that emerged from the conference that carers have their own needs; are expert partners in care; need support in every setting; need to be acknowledged into bereavement; and that caring shouldn't be a fight. The report has been produced in partnership with Age UK, the Carers Trust, Carers UK, Help the Hospices, Macmillan Cancer Support, Marie Curie Cancer Care, and Sue Ryder. (RH)

ISBN: 1898915954

From : National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.
www.ncpc.org.uk/dementia

2012

Care at the end of life for people with dementia living in a care home: a qualitative study of staff experience and attitudes; by Gill Livingston, Catherine Pitfield, Jackie Morris ... (et al).

International Journal of Geriatric Psychiatry, vol 27, no 6, June 2012, pp 643-650.

The present study aimed to examine barriers and facilitators to care home staff delivering improved end-of-life care for people with dementia. Individual qualitative interviews of 58 staff in a 120-bed nursing home where the staff and the residents' religion differed were carried out. Interviews continued until a maximum variation

sample was achieved and theoretical saturation was reached. Study findings revealed that the staff felt warmly towards the residents and felt they could recognise when they were near death. However nurses and doctors did not see themselves as a team and communicated poorly with relatives about approaching death. The staff used opaque euphemisms and worried about being blamed. They were often unaware of or had concerns about the validity of advance care plans. They knew of the religious rituals around death but frequently misunderstood religious tradition. The authors conclude that staff require education and support about discussing and implementing plans around care at the end of life in dementia and about cultural issues around death to improve practice. This would enable the staff to implement advance care plans, knowing that they would be supported. Education would encompass communicating the complicated, unpredictable path of dementia near the time of death explicitly but sensitively, including recognition that people often do not hear difficult messages and are unable to take in large quantities of information at once. Staff need to know about the resident's religious and cultural ideas as well as ritual practice. (JL)

ISSN: 08856230

From : <http://www.interscience.wiley.com/journal/gps>

Decision-making in older adults with serious illness: barriers to the goals of care discussion; by Rangaraj K Gopalraj, Laura J Grooms, Belinda K Setters ... (et al).

Aging Health, vol 8, no 4, August 2012, pp 367-376.

Individualising the goals of care discussion is challenging, especially at the end of life. This article explores some difficulties with goals of care planning using a clinical scenario involving a cognitively impaired older African-American woman with advanced chronic lymphocytic leukaemia and dementia facing a life-threatening condition. Physicians should personalise divergent goals such as a cure, rehabilitation, life-prolonging care and comfort care after factoring in individual patient preferences and disease trajectories. This case illustrates the barriers to the goals of care discussion: lack of education about the disease progression, poor communication techniques, poor language choice, not having proper decision-makers present and lack of trust between the decision-maker and the healthcare team. Harnessing technology can cause breakthroughs in the future. (JL)

ISSN: 1745509X

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

Do models of care designed for terminally ill 'home alone' people improve their end-of-life experience?: a patient perspective; by Samar Aoun, Moira O'Connor, Kim Skett ... (et al.): Wiley-Blackwell, November 2012, pp 599-606.

Health and Social Care in the Community, vol 20, no 6, November 2012, pp 599-606.

Palliative care patients who live alone report greater psychological distress, and are less likely to die at home than those living with a family carer. However, there is a lack of research on the value of models of care that specifically address this disadvantage. This article describes the experiences of terminally ill 'home alone' people using one of two models of care aimed at maintaining participants' need for independent living, focusing on the effect of these two models of care on their physical, social and emotional needs. 26 palliative care patients of Silver Chain Hospice Care, in Western Australia, were randomly assigned to either having a personal alarm or additional care-aide hours in their home. An in-depth qualitative study was conducted in two phases in 2010 using face-to-face interviews. The care-aide model of care resulted in benefits such as easing the burden of everyday living; supporting well-being; enhancing quality of life and preserving a sense of dignity; and reducing loneliness and isolation. The personal alarm model of care imparted a sense of security; provided peace of mind; and helped to deal with feelings of isolation. Participants in both groups felt that they could remain at home longer. By providing a safer, more secure environment through the use of a personal alarm or additional care-aide hours, patients were able to continue their activities of daily living, could build a sense of 'normality' into their lives, and they could live independently through support and dignity. (JL)

ISSN: 09660410

From : wileyonlinelibrary.com/journals/hsc

Dying to know: [DVD]; by Helen Reading, National Council for Palliative Care - NCPC; Red TIE (theatre company); pFlix Films. London: pFlix Films, for the National Council for Palliative Care, 2012, 1 DVD (Dying Matters).

'Dying to know' is an intergenerational drama about the difficulties and benefits of talking about the end of life. It tells the story of a family trying to come to terms with the imminent death of a much-loved and close relative. The film is based on a play commissioned by the Earl Mountbatten Hospice on the Isle of Wight and written by Helen Reading, Director of the Isle of Wight Red TIE theatre company. The script was adapted by Dying Matters and pFlix Films to further promote the importance of end of life discussions. Dying Matters is a national coalition led by the National Council for Palliative Care (NCPC), which aims to ask such questions and to

change public knowledge, attitudes and behaviours towards death, dying and bereavement (see www.dyingmatters.org). (RH)

Price: £6.00 for Dying Matters members

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

Final chapters: writing about the end of life: winning and highly commended works; by Dying Matters Coalition; National Council for Palliative Care - NCPC. London: Dying Matters Coalition, 2012, 65 pp.

In 2021, the Dying Matters Coalition ran the Final Chapters creative writing competition as part of its work to encourage more open discussion of end of life issues. This booklet contains 15 winning and highly commended works selected from almost 1,400 entries. (RH)

Price: £6.00

From : Dying Matters Coalition, The Fitzpatrick Building, 188-194 York Way, London N7 9AS. www.dyingmatters.org.uk

Guidelines for nursing homes delivering end-of-life care to residents across the island of Ireland; by Suzanne Cahill, Daphne Doran, Max Watson.: Emerald, March 2012, pp 60-70.

Quality in Ageing and Older Adults, vol 13, no 1, March 2012, pp 60-70.

This study was undertaken as part of the Living with Dementia programme based in the School of Social Work and Social Policy, Trinity College Dublin. It aim was to contribute to improving quality of life for people with end-stage dementia living in residential care settings, by investigating the experiences of aged spouses whose relatives died with end-stage dementia in nursing homes in both Northern Ireland (NI) and the Republic of Ireland (RoI). A second aim was to develop guidelines for nursing home staff for the delivery of quality care to residents with end-stage dementia in residential institutions. The study had two phases. Phase one involved conducting in-depth qualitative interviews with spouse caregivers whose relatives had died from dementia in long-stay care environments. Phase two entailed incorporating the information gathered through the in-depth interviews into draft guidelines and disseminating these to a multi-disciplinary group of health service professionals for their critical appraisal and ratification. The findings showed that most spouses deemed the end of life (EoL) care that was delivered to be of high quality, with person-centred, individual, kind, professional care being highly valued. Areas of dissatisfaction noted included poor communication, lack of involvement in key decision making, and poor symptoms control. Based on the study's findings, guidelines for the delivery of quality care in long stay residential institutions were developed in consultation with eight health service professionals. The authors hope these guidelines will contribute to improvements in the care of people with dementia at end of life, and will form the basis for the future development of policy, practices and procedures. (RH)

ISSN: 14717794

From : www.emeraldinsight.com/journals

The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life: research report; by Xavier Chitnis, Theo Georghiou, Adam Stevenson (et al), Nuffield Trust; Marie Curie Cancer Care. London: Nuffield Trust, November 2012, 62 pp (Evidence for better health care).

Although most people would prefer to die at home, more than half of all deaths in England and Wales are in hospital. The Marie Curie Nursing Service (MCNS) provides home-based end-of-life care to around 28,000 people at the end of life in the UK every year. Marie Curie Cancer Care commissioned the Nuffield Trust to evaluate the effect of its end of life home-based nursing service, by racking the experiences of more than 29,000 people who received care from MCNS, comparing their outcomes to a "control" group of end of life patients with similar circumstances who had not received care from Marie Curie. This report outlines the study's methods and results. It found that whereas 76.7% of those who received MCNS care died at home and only 7.7% died in hospital, 35% of the "controls" died at home and 41.6% died in hospital. The report also presents results concerning the effect of the MCNS on hospital use and the impact of the service on hospital costs. There is evidence that home-based nursing care can reduce hospital use at the end of life and help more people to die at home. In a difficult financial climate, there is a compelling case for service models other than hospital care in the last stages of life. This report is also available as a download (<http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing>). (RH)

Price: £5.00

From : The Nuffield Trust, 59 New Cavendish Street, London W1G 7LP. Website: <http://www.nuffieldtrust.org.uk>

Managing multiple goals in family discourse about end-of-life health decisions; by Allison M Scott, John P Caughlin.

Research on Aging, vol 34, no 6, November 2012, pp 670-691.

Previous research on end-of-life communication in families has largely considered whether family members have talked about end-of-life healthcare (quantity of talk) but not whether certain characteristics of that discourse matter (quality of talk). In this study, the authors adopted a multiple goals theoretical perspective to examine discursive features that individuals use to manage goal dilemmas in family conversations about end-of-life health choices. Discourse analysis of end-of-life conversations between 121 older adults and their adult children showed that participants attended to relevant task, identity, and relational goals in ways that affirmed or threatened these goals, and the ways in which certain goals were accomplished had implications for how (and whether) other goals were pursued. Findings suggest that end-of-life talk in families is most effective when family members are able to address the task of discussing end-of-life decisions, while also attending to the relevant identity and relational implications of such conversations. (RH)

ISSN: 01640275

From : www.roa.sagepub.com

Older people dying with dementia: a nationwide study; by Koen Meeussen, Lieve Van den Block, Michael Echteld (et al).

International Psychogeriatrics, vol 24, no 10, October 2012, pp 1581-1591.

Large-scale nationwide data describing the end-of-life characteristics of older people with dementia are lacking. This paper describes the dying process and end-of-life care provided to older people with mild or severe dementia in Belgium, compared to older people dying without dementia. A nationwide retrospective mortality study was conducted, via a representative network of general practitioners (GPs) in 2008 in Belgium, with weekly registration of all deaths (aged 65+) using a standardised form. GPs reported on diagnosis and severity of dementia, aspects of end-of-life care and communication, and on the last week of life in terms of symptoms that caused distress as judged by the GP, and the patients' physical and cognitive abilities. 31% of the sample (1,108 deaths) had dementia (43% mildly, 57% severely). Of these, 26% died suddenly, 59% in care home, and 74% received palliative treatment, versus 37%, 19%, and 55% in people without dementia. GP-patient conversations were less frequent among those with (45%) than those without (73%) dementia, and 11% of both groups had a proxy decision-maker. During the last week of life, physical and psychological distress was common in both groups. Of older people with dementia, 83% were incapable of decision-making and 83% were bedridden, both significantly higher percentages than found in the group without dementia (24% and 52%). Several areas of end-of-life care provision could be improved. Early communication and exploration of wishes and appointment of proxy decision-makers are important components of an early palliative care approach which appears to be initiated too infrequently. (RH)

ISSN: 10416102

From : www.journals.cambridge.org/ipg

Open to all?: Meeting the needs of lesbian, gay, bisexual and transgender people nearing the end of life: [DVD]; by National Council for Palliative Care - NCPC; Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations; pFlix Films. London: pFlix Films, for the National Council for Palliative Care, 2012, 1 DVD.

This DVD accompanies the 'Open to all?' report on end of life care for lesbian, gay, bisexual and transgender people (LGBT). The film comprises the personal experiences of LGBT people nearing the end of life and those caring for them. It highlights the importance of meeting everyone's end of life needs appropriately and sensitively, whatever their sexual orientation and/or gender identity. (RH)

Price: £5.00 (free to NCPD subscribers)

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

Preferences for end-of-life treatment: concordance between older adults with dementia or mild cognitive impairment and their spouses; by Liat Ayalon, Yaacov G Bachner, Tzvi Dwolatzky (et al).

International Psychogeriatrics, vol 24, no 11, November 2012, pp 1798-1804.

There is considerable debate about the ability of proxies to adequately reflect patients' preferences regarding end-of-life care, when patients are no longer capable of stating their preferences. This Israeli study evaluated concordance in end-of-life preferences between patients with mild cognitive impairment (MCI) or dementia and their spouses. A cross-sectional sample of 106 respondents (53 couples) was recruited in two psychogeriatric clinics. Bivariate analyses were conducted to evaluate the degree of agreement between the patients' preferences and those of their spouses. Patients were more likely to opt for more treatment than their spouses. Moderate agreement between patients and spouses was evident for preferences regarding end-of-life decisions for the

patients. There was little concordance between the wishes of spouses regarding their own preferences and what they wanted for the patient or what the patient wanted. When incorrectly predicting patients' preferences, spouses were more likely to ask for treatment. The results show that regarding end-of-life preferences for patients, there is moderate agreement between patients and their spouses, but limited evidence for projection of spouses' preferences on patients (i.e. the spouse making a prediction based on own wishes). Potential differences in end-of-life preferences between older adults with MCI or mild dementia and their caregivers should be taken into consideration in the preparation of advance care planning. (RH)

ISSN: 10416102

From : www.journals.cambridge.org/ipg

Rising to the Prime Minister's challenge on dementia: a spotlight on end of life care: a National Council for Palliative Care briefing for delegates at the 7th Annual Conference on Dementia and End of Life Care, December 2012; by National Council for Palliative Care - NCPC. London: National Council for Palliative Care - NCPC, 2012, folded sheet.

The Prime Minister launched his Challenge on Dementia on 26 March 2012. This leaflet suggests that achieving a good death for the person with dementia is possible, and cites three examples of good practice. It lists other resources on the topic. (RH)

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

The route to success in end of life care: achieving quality for lesbian, gay, bisexual and transgender people; by Bridget Moss, Tes Smith, Kathryn Almack, National End of Life Care Programme, NHS, Department of Health - DH; St Helena Hospice, Colchester; University of Nottingham. [London]: National End of Life Care Programme, 2012, 34 pp.

The Department of Health's End of Life Care Strategy (DH, 2008) emphasised the need to raise the quality of care provided to dying people and their loved ones. This practical implementation document aims to provide a guide for everyone working with lesbian, gay, bisexual and transgender (LGBT) people, and for LGBT people themselves, whether dying or receiving end of life care. It is intended to support practitioners and staff caring for LGBT people to engage with key professionals, and to ensure that those who may be in the last months of life receive high quality end-of-life care. The guide follows the six steps of the End of Life Care Pathway laid out in the national End of Life Care Strategy (2008), beginning with initiating discussions as end-of-life approaches and concluding with care after death. Each section outlines the relevant steps of the pathway, identifies issues to consider about the individual's care, and links to the practitioner and/or staff role in that care. The guide includes case studies highlighting best practice, and suggests further information resources. (RH)

From : www.endoflifecareforadults.nhs.uk

Spirituality and end of life issues: a review; by Gillian A Reid.

Journal of Religion, Spirituality & Aging, vol 24, nos 1-2, 2012, pp 120-130.

This article explores theories related to the development of spirituality and its relationship to end of life circumstances. It also considers the source of spiritual well-being, and its place in the context of the third (older, but still living independently) and fourth (frail elderly, needing care support) stages of life; plus how a sense of spirituality affects and hopefully enhances the end of life experience, increasing resilience to adverse events that might otherwise hasten death. It concludes that spiritual as well as religious issues are important for people facing terminal illness and death. (JL)

ISSN: 15528030

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

Understanding patterns of health and social care at the end of life: research summary; by Theo Georghiou, Sian Davies, Alisha Davies, Martin Bardsley, Nuffield Trust; National End of Life Care Intelligence Network. London: Nuffield Trust, October 2012, 11 pp (Evidence for better health care).

The 'End of life care strategy' (Department of Health, 2008) aims to help people have the care support they need beyond the acute hospital setting. This research summary highlights key findings from a study of over 73,000 people in England which investigated how often these individuals received social care services during the last 12 months of their lives. It draws on health and local authority social care records from 7 different local authority areas across England. Using this data, an analysis was conducted to link social care and NHS records at person level, to identify uptake and associated costs of NHS and social care services. Survey results show that many people with terminal illness would prefer to die with appropriate support at home rather than in hospital. This means developing a range of support services at the end of life, spanning both health and social care. Despite the importance of social care in supporting individuals at the end of their lives, there are remarkably few studies that look at how often these people receive social care services. (RH)

From : The Nuffield Trust, 59 New Cavendish Street, London W1G 7LP. Website:
<http://www.nuffieldtrust.org.uk>

2011

Advance care planning for people with dementia: a review; by Karen Harrison Denning, Louise Jones, Elizabeth L Sampson.

International Psychogeriatrics, vol 23, no 10, December 2011, pp 1535-1551.

Few people with dementia have made advance plans for their health care. Advance care planning (ACP) is a process of discussion between an individual and their care providers that takes account of wishes and preferences for future care. The authors aimed to examine the facilitators and inhibitors to ACP in people with dementia. They also aimed to identify key themes in the literature and to critically review the methodologies used. They conducted a systematic search of English language databases including PubMed, CINAHL, AMED, PsychINFO, EMBASE and BNI. They included empirical studies which reported the characteristics of the patient population, the type of advance care planning used and the study setting, and which involved people with dementia, family members or professional carers. 17 studies were identified (11 quantitative methods, one qualitative and five mixed methods). One ACP intervention which changed outcomes for people with dementia was found. Four key themes were identified. First, there is a point at which cognition decreases critically so that an advanced care plan can no longer be made. Second, factors present in family carers and professionals can influence decision-making and the ACP process. Third, ACPs are affected by preferences for life sustaining treatments; ACP in dementia may differ from other illness groups. Lastly, there is a need for education relating to ACP. The current evidence base for ACP in dementia is limited. Since UK government policy recommends that all people should engage in ACP, more evidence is needed to understand the feasibility and acceptability of advanced care plans for people with dementia. (RH)

ISSN: 10416102

From : www.journals.cambridge.org/ipg

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 uncertainly 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/>

Difficult conversations: making it easier to talk to people with dementia about the end of life; by National Council for Palliative Care - NCPC; National End of Life Care Programme, NHS, Department of Health - DH. London: National Council for Palliative Care - NCPC, 2011, 22 pp.

This guidance aims to help carers and professionals caring for someone with dementia to open up conversations about end of life wishes and preferences. It is based on conversations with around fifty people affected by dementia, people with dementia, carers and former carers. The booklet also suggests other useful resources, and is part of a range of materials published as part of NCPC's role as lead organisation of the Dying Matters Coalition, which aims to raise awareness of dying, death and bereavement. (RH)

Price: £5.00

From : National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.
www.ncpc.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 - NCPC; 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>

End-of-life care: Japan and the world: international comparison study on death and dying in place: abbreviated version; by International Comparative Study on Ideal Terminal Care and Death; International Comparative Study on Terminal Care System; International Longevity Center, Japan - ILC-Japan. Tokyo: International Longevity Center, Japan - ILC-Japan, March 2011, 48 pp.

The research summarised in this report aims to clarify differences in end-of-life care between Japan and seven other countries (France, UK, Israel, Australia, the Netherlands, South Korea and the Czech Republic). It looks at special features of such care, including ethical issues. (RH)

From : International Longevity Center (Japan), Toranomom 33 Mori-Building, 3-8-21 Toranomom, Minatoku, Tokyo, Japan. <http://www.ilcjapan.org> email: ilcjapan@mba.sphere.ne.jp

Failing to plan is planning to fail: advance care planning for people nearing the end of life; by Rachel Newman, Keri Thomas.

Aging Health, vol 7, no 5, October 2011, pp 677-680.

This article briefly summarises proceedings of the second International Society of Advance Care Planning and End of Life Care (ACPEL) conference, held in London on 22-24 June 2011. With over 400 delegates from across the world representing 22 different countries, this conference represents the increasing international recognition of the importance of holding and recording advance care planning discussions with older people nearing the end of their lives. (JL)

ISSN: 1745509X

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

Geriatricians' views of advance decisions and their use in clinical care in England: qualitative study; by Catherine Jane Bond, Karen Lowton.

Age and Ageing, vol 40, no 4, July 2011, pp 450-456.

An anticipatory decision document records a person's wishes regarding medical treatment at a time when they have capacity to make choices, to be enacted when that capacity is lost. In England and Wales an advance decision to refuse treatment (ADRT), a legally binding document, is currently rarely used. A disparity is suggested to exist between physicians' support for anticipatory decisions in principle and their lack of impact on decision-making in practice. The aim of the present study was to elicit geriatricians' views on advance decisions and their use in decision-making in England. Study findings showed that geriatricians held positive views on anticipatory decisions in principle. In practice, they reported being highly likely to follow a decision which was in line with their clinical view. They would also favour an ADRT which was prescriptive in terms of the situation and treatment to which it applied. However, geriatricians expressed concerns in relation to patient understanding of the role and limits of these documents. Participants expressed discomfort in following an ADRT which, in their professional opinion, did not represent the patient's best interests, despite it being a legally binding document. A conflict between doctors' beneficence and patients' autonomy was apparent, with geriatricians differing in their views on how ADRTs should fit into medical decision-making, and particularly how far anticipatory decisions can represent ongoing patient autonomy. Despite its status in law, an ADRT which conflicts with a geriatrician's clinical opinion may not be implemented, resulting in a breach of the Mental Capacity Act. (JL)

ISSN: 00020729

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

Improving end-of-life care for people with dementia; by Elizabeth L Sampson, Alistair Burns, Mike Richards.

British Journal of Psychiatry, vol 199, no 5, November 2011, pp 357-359.

One in three adults over the age of 60 years will die with dementia. Most will have complex physical and psychological needs. This paper looks at why people with dementia experience poor end-of-life care, what are the end-of-life care needs of people with dementia and their families, and how such care for this client group can be improved. The authors refer to recent government strategies aimed at improving services, eg. The National Dementia Strategy, and the National End of Life Care Strategy. However the research has tended to focus on people with advanced dementia and little is known about people in the earlier stages of dementia who may be dying from other chronic comorbid conditions. New interventions on service models to improve care will have to be developed carefully, taking into account the wide range of settings in which people with dementia die. (JL)

ISSN: 00071250

From : <http://bjp.rcpsych.org>

Living through end-stage dementia: the experiences and expressed needs of family carers; by Chris Shanley, Cherry Russell, Heather Middleton, Virginia Simpson-Young.

Dementia: the international journal of social research and practice, vol 10, no 3, August 2011, pp 325-340.

The study focused on the experiences and needs of family carers of people with end-stage dementia. The project involved in-depth, qualitative interviews with 15 carers. The major themes emerging from the accounts of participants' experiences were: getting support; having to trust others with care; managing the loneliness of being a carer; witnessing a loved one fade away; anticipating and experiencing death; and re-establishing life after the funeral. Carers expressed a range of instrumental and psychosocial needs. The study provided a more personal account of the caring experience than much of the related literature. It emphasised the need of carers for genuine understanding and connection - from family and friends as well as healthcare staff. The study highlights the amount of support carers can provide to each other through support groups and associated friendships, and stresses the importance of healthcare staff acknowledging and respecting this capacity of carers. (JL)

ISSN: 14713012

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

Nurse-led support improves dementia care at end of life; by Amanda Thompsell, Nicola Easton, Min Stacpoole.: Hawker Publications, November/December 2011, pp 18-19.

Journal of Dementia Care, vol 19, no 6, November/December 2011, pp 18-19.

The authors report on the benefits of a nurse facilitating good end of life care for people with dementia in the community, including those in care homes. The modernisation initiative End of Life Care Programme, 2008-2011, aims to improve end of life care for people with dementia in Lambeth and Southwark, London. The Nurse Facilitator for End of Life Care role was created to encourage and support best practice, to combine end of life care with dementia care skills, and to enhance the skills of care staff. The facilitator worked closely alongside

nurses and care staff in several ways, through observation, carrying out pain assessments and sharing tasks. (RH)

ISSN: 13518372

From : www.careinfo.org

Older people with heart failure and general practitioners: temporal reference frameworks and implications for practice; by Susan Waterworth, Merryn Gott, Deborah Raphael, Sarah Barnes.

Health and Social Care in the Community, vol 19, no 4, July 2011, pp 412-419.

Chronic illness changes one's sense of time, and chronic disease management and palliative care have implications for health professionals' use of time. The aim of the study was to identify the temporal reference frameworks that structure and give meaning to the experiences of time for older patients with heart failure and their general practitioners (GPs). Secondary analysis of qualitative data collected from two longitudinal studies, one in the United Kingdom and the other in New Zealand, was carried out. The UK study involved interviews with 44 older people with heart failure and nine focus group discussions with primary health professionals during 2004-2005. The NZ study involved 79 interviews with 25 older people with heart failure and 30 telephone interviews with GPs during 2008-2009. Different temporal reference frameworks were identified for both patients and GPs. 'Clock time' was evident in how it structured the consultations. Both patients and GPs valued 'needing time', however there were tensions between 'needing time' and 'wasting time'. For some GPs this involved creating space for 'emotional time'. Being 'known over time' was important to both patients and GPs. The article concludes that understanding these multiple times is important for improving the quality of care for older people. (JL)

ISSN: 09660410

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

Open to all?: Meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life; by Alice Fuller, Sam Turner, Mark Delacour, National Council for Palliative Care - NCPC; Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations. London: National Council for Palliative Care, 2011, 27 pp.

The National Council for Palliative Care (NCPC) and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations set out to gauge experiences and current practices from both sides: LGBT people who have or will need to use palliative care services and services providing end of life care in the community. This document presents the findings of a short survey conducted in 2010 regarding what further work was needed. 739 responses were received, and the focus is on answers to the open-ended questions on matters such as treating people equally, and tackling homophobic or transphobic attitudes. The report concludes that end of life service providers need to do all they can to make their services truly open to all, and to promote themselves to the lesbian, gay, bisexual and transgender (LGBT) communities in their local areas. (RH)

Price: £10.00 (free to 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

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

Ageing 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>

Partner care at the end-of-life: identity, language and characteristics; by Anne Corden, Michael Hirst.

Ageing and Society, vol 31, part 2, February 2011, pp 217-242.

In this paper the authors present data from research on couples where one partner died, drawing on a study of the financial implications of a partner's death. Information was gathered from a study based on the British Household Panel Survey of over 750 couples separated by death, and from interviews with 44 recently bereaved women and men from all age groups. The article describes the findings on adopting an identity of caregiving, people's characteristics and circumstances, health care needs, service contacts, and trends over time, and

discusses models showing a range of factors and their success in predicting whether people described themselves as providing care. The study findings showed that carer self-identification was influenced by the partner's health care needs and service contacts, including receipt of welfare benefits. The authors conclude that further research is required to investigate the circumstances under which providing care equates with adopting or assigning a carer identity. (JL)

ISSN: 0144686X

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

Pharmacotherapy at the end-of-life; by Denis O'Mahony, Marie N O'Connor.

Age and Ageing, vol 40, no 4, July 2011, pp 419-422.

Older people reaching the end of life are particularly at risk from the harmful effects of inappropriate drug use. These drugs may also be highly expensive. End-of-life pharmacotherapy is sometimes perceived to be complex and challenging, probably unnecessarily. This relates in part to the poorly developed evidence base and lack of high-quality research in this area. In this article the authors examine some of the key issues relating to pharmacotherapy in end-of-life patients, namely (i) the guiding principles of drug selection, (ii) the main drugs and drug classes that are best avoided, (iii) the benefits of 'oligopharmacy' (i.e. deliberate avoidance of polypharmacy) in end-of-life patients. (JL)

ISSN: 00020729

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

Relatives meetings: can we discuss end of life care?; by Amanda Thompsell, Dave Bell.: Hawker Publications, July/August 2011, pp 20-21.

Journal of Dementia Care, vol 19, no 4, July/August 2011, pp 20-21.

The authors share learning from Facing the Future, a project which involved meeting with relatives' groups to talk about end of life issues. Based in south London, the project is a peer support service for carers of people with dementia. It focuses on providing support for carers of people with dementia facing end of life care dilemmas, in the context of objectives in the National Dementia Strategy and the End of Life Care Strategy. The project recruited volunteers who had cared for someone with dementia who had died at least a year before to become peer supporters, who asked care homes about speaking at their regular relatives meetings to introduce the volunteers and generate discussion. The article discusses issues arising from the meetings, including the support needs of the volunteer carers and relatives, and the importance of involving staff. (RH)

ISSN: 13518372

From : www.careinfo.org

Researching the end-of-life in old age: cultural, ethical and methodological issues; by Liz Lloyd, Kate White, Eileen Sutton.

Ageing and Society, vol 31, part 3, April 2011, pp 386-407.

Third of four articles that together make up a special issue on research methodology and ageing. This article looks at how increased life expectancy coupled with the rise in chronic disease has had a significant impact on dying trajectories in old age. This poses ethical and methodological challenges for researchers, not least because it is often difficult to establish whether an older person is dying from, as opposed to living with, one or more diseases. This article reports a comprehensive literature review of empirical research on the end-of-life in old age. It presents two inter-related themes by first exploring the social and cultural contexts of death and then critically analysing the methods and ethical approaches adopted by researchers. Material was drawn from both cross-cultural studies and studies in which cultural factors were of prime interest, and were selected with a view to investigating the concept of a good death in old age. First, the article examines the evidence of cultural similarities and differences and the impact of social and cultural change on ideas concerning a good death. It then identifies contemporary influences and pressures on end-of-life care for older people. Finally, the article explores the significance of communication and the roles of families and service providers in this arena. (JL)

ISSN: 0144686X

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

We are living well but dying matters: [DVD]; by National Council for Palliative Care - NCPC; National End of Life Care Programme; CHANGE. [Leeds]: CHANGE, 2011, 1 DVD (Dying Matters).

People with learning disabilities need to be able to acknowledge their loss and to mourn when someone close to them dies. They also need to be included in important decisions being made around their end of life care (especially their own). to be able to ask questions, and to have their emotional needs met and dying wishes recorded. This DVD was funded by the National Council for Palliative Care (NCPC) and the National End of Life Care Programme. In the DVD, people with learning disabilities tell their stories and share their wishes to

support other people with learning disabilities to become more comfortable talking about dying, death and bereavement. (RH)

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

2010

Achieving Gold Standard end-of-life care for people with dementia in care homes; by Nicola Wheeler, Jan R Oyeboode.: Hawker Publications, Jan/Feb 2010, pp 36-39 (Research focus).

Journal of Dementia Care, vol 18, no 1, Jan/Feb 2010, pp 36-39 (Research focus).

Care homes play a major role in supporting people with dementia at the end of their lives. In seeking to understand the views of staff on the care they provide, the authors held focus groups with a range of staff in nine care homes in the West Midlands. Staff discussed issues such as where death should take place, how they planned end-of-life care, and how they coped with death. This article outlines findings on admission to hospital at end of life, liaison with relatives, and advance statements. The implications for practice of these findings are discussed. (RH)

ISSN: 13518372

Artificial nutrition and hydration at the end of life; by Roschelle A Heuberger.

Journal of Nutrition for the Elderly, vol 29, no 4, 2010, pp 347-385.

This article presents a comprehensive review of controversies surrounding artificial nutrition and hydration (ANH) for terminally ill patients in the United States. Covers legal and ethical issues (including ANH in dementia care) and describes different clinical methods - eg. tube feeding, non-oral hydration, total parenteral nutrition and hydration. Also looks at religious issues for different religions. Concludes with a look at personal and professional issues as well as fiscal aspects of end of life care. (JL)

ISSN: 01639366

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

Barriers to dying at home: the impact of poor co-ordination of community service provision for patients with cancer; by Mary O'Brien, Barbara Jack.

Health and Social Care in the Community, vol 18, no 4, July 2010, pp 337-345.

For patients dying of cancer, there is an emphasis on giving choice regarding preferred location for care, with the option of dying at home, which is integral to UK government health initiatives such as the End of Life Care Programme. However, patients continue to be admitted to hospital in the terminal phase of their illness when they have expressed a desire to die at home. A qualitative study, using two audio tape-recorded focus group interviews, with a purposive sample of district nurses and community specialist palliative care nurses (19) was undertaken across two primary care trusts in the north west of England. Data were analysed using a thematic analysis approach. From a service provision perspective, the results reveal that poor discharge planning and co-ordination, difficulty in establishing additional equipment and services together with inadequate out of hours medical provision were all factors contributing to hospital admissions for patients with cancer in the last hours and days of life, and thus were barriers to dying at home. (KJ)

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From : [http://www.blackwellpublishing.com/hscDOI: 10.1111/j.1365-2524.2009.00897.x](http://www.blackwellpublishing.com/hscDOI:10.1111/j.1365-2524.2009.00897.x)

Biopsychosocial and end-of-life care: timely intervention for the elderly; by Pierre Mallia.: International Institute on Ageing (United Nations - Malta), May 2010, pp 22-29.

BOLD, vol 20, no 3, May 2010, pp 22-29.

End-of-Life decisions are not only about palliation and advanced directives. The biopsychosocial model is a paradigm which helps identify the psychological and social factors and barriers which help towards a realistic balance towards the end of life. Spirituality in particular, is not merely religious practices and the presence of pastoral care, but is about achieving balance, harmony and meaning. New models can help for older people in extending the concept of palliative care at the very end of terminal diseases to more chronic and disabling conditions which affect the outcome. Moreover, one should not consider end-of-life decision based merely on age, but in the case of the elderly palliation and other biopsychosocial decisions which would otherwise be directed only in terminal illness, need to be considered earlier. (RH)

ISSN: 10165177

From : <http://www.inia.org.mt>

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@ncpc.org.uk Website: www.ncpc.org.uk

Challenges to improving end of life care of people with advanced dementia in the UK; by Ingela C V Thuné-Boyle, Elizabeth L Sampson, Louise Jones (et al).

Dementia: the international journal of social research and practice, vol 9, no 2, May 2010, pp 259-284.

The end of life care received by patients with advanced dementia and their carers is of increasing importance as the incidence of dementia is set to rise in the next 30 years. Currently, inappropriate admissions to hospital are common in the UK and patients are less likely to be referred to palliative care services, receive less pain control, but undergo more invasive interventions compared to their cognitively intact counterparts. Patients and families are seldom informed of the terminal nature of dementia and advance care planning discussions are rare. The aim of this study was to improve the understanding of end of life care needs for this patient group and their carers, and to use this information to devise an intervention to improve care. Qualitative data were obtained from relatives of 20 patients with advanced dementia admitted to an inner London teaching hospital acute National Health Service (NHS) Trust and 21 health care professionals involved in their care. Framework analysis was used to analyse the transcripts. The results showed that participants' understanding of dementia and its likely progress was poor. Provision of information regarding the future was rare despite high information needs. Attitudes regarding end of life care were often driven by the participant's illness awareness. These attitudes served to guide the decision making process and appear to be a major barrier to the provision of more appropriate care. Implications for patient care are discussed and suggestions for future interventions are made. (KJ/RH)

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From : <http://dem.sagepub.com/doi/10.1177/1471301209354026>

Cuts in social care could increase pressure on hospitals to care for patients at end of life; by Adrian O'Dowd.

British Medical Journal, vol 341, no 7785, 11 December 2010, P 1239.

Summarises a report from the Nuffield Trust, 'Social Care and Hospital Use at the End of Life', which warns that hospitals in England could face increased pressure caring for patients at the end of life if social care budgets are cut. The full report can be downloaded at www.nuffieldtrust.org.uk/uploadedFiles/Publications/Social_care_and_hospital_use-full_report_061210.pdf (JL)

ISSN: 09598138

From : www.bmj.com

Deaths in older adults in England; by Kate Ruth, Julia Verne, National End of Life Care Intelligence Network - NEoLCIN, NHS End of Life Programme, Department of Health - DH; South West Public Health Observatory - SWPHO. London: National End of Life Care Intelligence Network, October 2010, 68 pp.

The South West Public Health Observatory (SWPHO) has been commissioned to produce key outputs and analyses for the National End-of-Life Care Intelligence Network (NEoLCIN), including the national End of Life Care Profiles, available on the Network's website (www.endoflifecare-intelligence.org.uk). This is the fourth report published by the Network, and looks at deaths of people aged 75+ to examine differences in place and underlying cause of death by age band from old to extreme old age. It finds that there appears to be a trend in all age groups for the proportion of deaths in hospital to have increased in the period 1995 to 2008; this has since levelled off. The report also examines deaths by socio-economic status. While more deaths in people aged 75+ occurred amongst people living in more deprived areas, the proportion of deaths in people aged 75+ in the most deprived areas decreased with increasing age. (RH)

Price: download

From : Download from: <http://www.endoflifecare-intelligence.org.uk/resources/publications/default.aspx#neolcin> (Author contact: South West Public Health Observatory, Grosvenor House, 149 Whiteladies Road, Bristol BS8 2RA.)

The differences between general care planning and decisions made in advance; by Sheila Joseph, National End of Life Care Programme, NHS, Department of Health - DH. [Leicester]: National End of Life Care Programme, 2010, 4 pp.

Advance care planning (ACP) is a process of discussion between an individual patient and care providers irrespective of discipline. The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes, and will usually take place in the context of an anticipated deterioration of the individual's condition in the future, with attendant loss of capacity make decisions and/or ability to communicate wishes with others. This pamphlet clarifies the differences between general care planning and three decisions that can be made in advance: advance care planning (ACP, or advance statement), advance decisions to refuse treatment (ADRT), and do not attempt cardiopulmonary resuscitation (DNACPR). Websites for further information are suggested. (RH)

From : National End of Life Care Programme, 3rd Floor, St John's House, East Street, Leicester LE1 6NB.

Difficult conversations: communicating with people with chronic obstructive pulmonary disorder about the end of life; by Jo Black, National Council for Palliative Care - NCPC. London: National Council for Palliative Care - NCPC, 2010, unnumbered (A5 booklet).

This booklet is for anyone caring for someone with Chronic Obstructive Pulmonary Disorder (COPD). It presents perspectives of around 60 people affected by COPD and describes views on thinking and talking about death and dying. A more detailed account of the conversations that informed this booklet is available on the NCPC website (www.ncpc.org.uk). The booklet is part of a range of materials published as part of NCPC's role as lead organisation of the Dying Matters Coalition, which aims to raise awareness of dying, death and bereavement. (KJ/RH)

Price: £5.00

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

Due respect and professional care in death; by David Jolley, Mike Tapley.

The Psychiatrist, vol 34, issue 4, April 2010, pp 143-145.

The Royal College of Physicians' Palliative Care Services: Meeting the Needs of Patients and the Department of Health's End of Life Care Strategy are important reports that signify a national and international determination to address the needs of people who are nearing their time of dying, and their families, with positive, well-informed professionalism. Despite the advances of medicine and improved social conditions, death will eventually supervene. Psychiatrists and other mental health workers encounter death, in anticipation of its coming and in its aftermath. They need to be aware of developments in the field of end-of-life care and contribute to developments which are occurring, as well as learn and assimilate better practices. (KJ/RH)

ISSN: 17583209

From : <http://pb.rcpsych.org/doi/10.1192/pb.bp.109.026260>

The dying art: [Social worker involvement with end-of-life care]; by Sally Gillen.

Professional Social Work, September 2010, pp 20-21.

This article highlights a report's findings published in 2010, that social workers are not sufficiently engaged in working with people, especially older people, who are near the end of their life; and saw in fact, that end of life care was not their responsibility. This situation should be improved with further training, especially from existing sources, such as that from the hospice movement. The featured report is published by the National End of Life Care Programme, entitled "Supporting People to Live and Die Well" and can be found on their website to download (www.endoflifecareforadults.nhs.uk/publications).

ISSN: 13523112

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

Dying for a change; by Charles Leadbeater, Jake Garber, Demos. London: Demos, 2010, 136 pp.

The institutionalised ways we cope with dying do not align with how most people aspire to die. Most people want to die with family and friends nearby, cared for, free from pain, with medical support available when needed. Yet most people will die in hospitals and care homes, often cut off from friends and family, dependent on systems and procedures that feel impersonal, over which they have little control and which too often offer them little dignity. The UK government spend large sums of taxpayer's money - at least £20 billion a year - on

services that leave too many people feeling confused, frustrated and distressed too much of the time. The country should be able to provide people with better ways to die. This paper argues for improvements to existing services: making end of life advance care plans the norm; training more in the medical profession in palliative care; and more greatly integrating the care services provided by the public, private and voluntary sectors. It also suggests radical innovations: a new infrastructure of home hospices, the creation of a compassionate care benefit and a properly trained volunteer support network providing palliative care - a perfect opportunity for the Big Society. The challenge is to help people to achieve what is most important to them at the end of life. Dying for Change describes how that challenge can be overcome. (KJ)

Price: £10.00 or download

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

Dying Matters Newsletter; by Dying Matters Coalition. London: National Council for Palliative Care - NCPC, March 2010, newsletter + 5 A5 pamphlets.

The Dying Matters Coalition is raising public awareness of dying, death and bereavement in England; it is led by the National Council for Palliative Care (NCPC). This particular issue of the newsletter was published during the first Dying Matters Awareness Week 15-21 March 2010, which saw events and activities taking place nationwide. A series of five pamphlets and a poster was also launched during the week which are designed to help people focus on talking about death and dying, especially during times of terminal illness or bereavement. (KJ/RH)

From : Dying Matters Coalition, The Fitzpatrick Building, 188-194 York Way, London N7 9AS.

www.dyingmatters.org

End of life care: a rapid response hospice at home service; by Carol Davis.

Nursing Older People, vol 22, no 4, May 2010, pp 22-24.

Many people would prefer to die at home. In line with recommendations on this in the Department of Health (DH) End of life care strategy (2008), the charity Sue Ryder Care piloted a rapid response care and palliative expertise at home initiative in Bedford. The project supported 17 patients to die in their own homes. Evaluation of the project will be shared with the local primary care trust (PCT) in the hope that it will continue to fund the service. Other community-based models of end of life care that the charity has developed are outlined. The author discusses the benefits of the scheme and feedback from the 17 families it helped. (RH)

ISSN: 14720795

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

End of life care for community dwelling older people with dementia: an integrated review; by Claire Goodman, Catherine Evans, Jane Wilcock (et al).

International Journal of Geriatric Psychiatry, vol 25, no 4, April 2010, pp 329-337.

An integrated review synthesised the qualitative and quantitative evidence on end of life care for community dwelling older people with dementia. English language studies that focused on prognostic indicators for end of life care assessment, support and/or relief, respite and educational interventions for community-dwelling older people with dementia were included. A user representative group informed decisions and the breadth of literature used. Each study selected was screened independently by two reviewers using a standardised checklist. 68 papers were included. Only 17% (12) exclusively concerned living and dying with dementia at home. 6 studies included direct evidence from people with dementia. The studies grouped into four broad categories: dementia care towards the end of life; palliative symptom management for people with dementia; predicting the approach of death for people with dementia; and decision-making. Most of the studies were descriptive. The few studies that developed dementia-specific tools to guide end of life care and outcome measures specific to improve comfort and communication demonstrated what could be achieved, and how much more needs to be done. Research on end of life care for people with dementia has yet to develop interventions that address the particular challenges that dying with dementia poses. There is a need for investigation of interventions and outcome measures for providing end of life care in the settings where the majority of this population live and die. (RH)

ISSN: 08856230

From : <http://www.interscience.wiley.com/journal/gpsdoi:10.1002/gps.2343>

Exceptional care at the end of life; by Lynne Greenwood.

Health Service Journal, no 6207, 20 May 2010, pp 20-21.

The 2008 end of life care strategy allocated £286m to primary care trusts (PCTs). This article looks at some of the innovations and improvements that are being made with this money. Examples range from a tool to manage the care of patients with uncertain prognosis, to facilities for newly bereaved relatives and carers. An example of the former is a form of personalised care called AMBER (assessment, management, best practice, engagement

for recovery). Funded by Guys' and St Thomas' Charity, AMBER has been developed in partnership with clinical specialists and patient and carer groups. An example of the latter is a new bereavement suite at Southend University Hospital Foundation Trust, which incorporates provision of a registrar on site to prevent relatives having to make a separate visit to register a death. (RH)

ISSN: 09522271

From : www.hsj.co.uk

The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives; by Jenni Burt, Cathy Shipman, Alison Richardson (et al).

Age and Ageing, vol 39, no 1, January 2010, pp 86-91.

There is limited understanding of symptoms and care in the last two months of life for adults dying from causes other than cancer. This study employed a retrospective cross-sectional survey of bereaved relatives. The survey took place across eight cancer networks in England. A random sample of 1,266 adults who registered a death occurring in someone aged 65 and over between August 2002 and February 2004 was drawn. VOICES (Views of Informal Carers - Evaluation of Services) questionnaires were sent to sampled informants by the Office for National Statistics (ONS) 3-9 months after the registration of the death. Differences in the reported experiences of cancer and non-cancer decedents in symptoms, treatment and care were assessed using Pearson's chi square test. Cancer decedents were significantly more likely than non-cancer decedents to have had pain (93% vs 79%, $P < 0.001$), nausea and vomiting (62% vs 40%, $P < 0.001$) and constipation (74% vs 66%, $P = 0.03$), whilst a greater proportion of non-cancer decedents experienced breathlessness (74% vs 65%, $P = 0.006$). Across both groups, less than half of the decedents were reported to have received treatment which completely relieved their symptoms some or all of the time. There were significant variations in the receipt of district nursing, general practitioner care and other health and social care and the reported quality of this care, for decedents dying of cancer and non-cancer causes. Further, informants for cancer deaths reported greater satisfaction with support received. There are important differences in the reported experiences of older adults dying from cancer and non-cancer causes in the last months of life, independent of age. (KJ/RH)

ISSN: 00020729

From : <http://www.ageing.oxfordjournals.org><http://www.bgs.org.uk>[doi:10.1093/ageing/afp212](https://doi.org/10.1093/ageing/afp212)

Following the money: findings from NPCC's survey to monitor the first year of investment in end of life care 2009/10; by National Council for Palliative Care - NCPC. London: National Council for Palliative Care, March 2010, 4 pp (Briefing 18).

In its election manifesto in 2005, the Government pledged to double the investment in palliative care. As a result, the Department of Health (DH) launched its first national End of Life Care Strategy for adults in England in 2008, with commitments being made to increase expenditure. The National Council for Palliative Care (NCPC) has received anecdotal reports that additional funds allocated to primary care trusts (PCTs) have not reached front-line services. This briefing outlines findings from a survey to ascertain whether strategic health authorities (SHAs), PCT commissioners and palliative care providers could account for the spending of these funds. 33 PCTs (35%) were unable to identify a specific amount as their initial budget for end of life care in 2009/10; more optimistically, other PCTs had a clearer understanding of what was included in their end of life care budgets; and two PCTs report on the areas of care included. Recommendations are made regarding greater transparency by PCTs and SHAs in using end of life care expenditure. (RH)

Price: £5.00 (FOC 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

Getting started: involving people with personal experience; by Jo Black, National Council for Palliative Care - NCPC. London: National Council for Palliative Care, June 2010, 10 pp.

'Getting started' is one of two documents about user involvement in end of life care, and serves as an introductory guide. It responds to some reasons why people do not get involved and provides some practical ideas about getting started and making further progress in this worthwhile work. (RH)

ISBN: 1898915814

Price: £2.50 (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

GMC guidance on end of life care: Important changes for clinicians take effect on 1 July; by Dominic Bell.

British Medical Journal, vol 340, no 7761, 26 June 2010, pp 1373-1374.

Guidance from the General Medical Council (GMC) on end of life care comes into force on 1 July 2010. Change became essential because of the Mental Capacity Act 2005 and after reviews reported how patients with

terminal illness are denied informed choice. This article notes some of the changes, the main one being that death should become an explicit discussion point when patients are likely die within 12 months. Other changes include the replacement of "artificial" with "clinically assisted" in relation to nutrition and hydration; and "best interests" with "overall benefit". The article notes subjects likely to provoke professional debate: decisions about cardiopulmonary resuscitation (CPR); resolving of clinical disagreements; administration of analgesia and sedatives at the end of life; and whether the guidance only applies to specialties managing progressive incurable diseases. The guidance is an important opportunity for the medical profession to re-establish public confidence that made this guidance necessary. The guidance, 'Treatment and care towards the end of life: good practice in decision making' can be found on the GMC website (at http://www.gmc-uk.org/guidance/ethical_guidance/6858.asp). (RH)

ISSN: 09598138

From : www.bmj.comBMJ2010;340:c3231

Interdisciplinary education in end-of-life care: creating new opportunities for social work, nursing, and clinical pastoral education students; by Cynthia Forrest, Christina Derrick. Binghamton, NY: Haworth Social Work Practice Press, 2010, pp 91-116.

Journal of Social Work in End-of-life & Palliative Care, vol 6, nos 1/2, 2010, pp 91-116.

This article describes an interdisciplinary, inter-university course that prepares social work, nursing and chaplaincy students for competent practice when working with individuals and families facing end-of-life circumstances. Built upon a teaching format that provides knowledge-to-skill-building opportunities, the course immerses students in a range of related content. To maximize integration, the course relies on interdisciplinary team teaching (building knowledge) followed by practice sessions (building skill), in which volunteer actors play the roles of care recipients. With year 3 completed, course administrators have important indicators of the course's effectiveness in offering content specific to end-of-life care using a combination of discipline-specific and interdisciplinary learning strategies. This process has provided valuable lessons related to the nature of interdisciplinary education in end-of-life care. (RH)

ISSN: 15524256

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

It's not just about heart failure: voices of older people in transition to dependence and death; by Susan Waterworth, Diane Jorgensen.

Health and Social Care in the Community, vol 18, no 2, March 2010, pp 199-207.

New Zealand's ageing population is predicted to increase from 12% in 2001 to 25% by the year 2051, similar to the worldwide trend of ageing. A high proportion of these people will have one or more chronic illnesses. Associated with the increase in survival is a growing body of research examining the needs of the older person with heart failure and finding particular problems with end of life care. Older people face many challenges in living with their heart failure, in particular the transition to dependence. This paper explores the experiences of older people living with heart failure and their transitions from independence to dependence, and for some, death. To study the transition, a longitudinal qualitative study using General Inductive approach was used. Participants were interviewed every 3 months for a 12-month period during 2006-2008. A total of 79 interviews with 25 people were completed. The findings showed that transition was not a simple linear process with the older person moving from one phase to another; instead their experiences illustrated the complexity of transitions they faced and what helped them to manage these. The older people in this study illustrated the importance of trust in health professionals, and believed they would receive good care. Their fears revealed concerns about being a burden as they deteriorate and becoming more dependent. Understanding the complex issues related to transition to dependence can provide health professionals with a framework for assessment and approaches to providing the support required. (KJ/RH)

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From : [http://www.blackwellpublishing.com/hscDOI: 10.1111/j.1365-2524.2009.00892.x](http://www.blackwellpublishing.com/hscDOI:10.1111/j.1365-2524.2009.00892.x)

The last year of life in Europe: regional variations in functional status and sources of support; by Karsten Hank, Hendrik Jurges.

Ageing and Society, vol 30, part 6, August 2010, pp 1041-1054.

This article aims to provide an initial account of the life circumstances of older people in 11 continental European countries during the year prior to their deaths. It focuses on regional variations in functional limitations and sources of support. The authors use logistic regression to analyse data from 523 end-of-life interviews in 2006-07, collected by the Survey of Health, Ageing and Retirement in Europe (Wave 2) about the respondents who had died since the baseline data collection in 2004-05. The prevalence of functional limitations was found to be fairly consistent across Northern, Central and Southern Europe. Significant regional differences existed, however, with regard to the deceased respondents' main sources of support and the locations of their

deaths. Northern Europeans were the least likely to receive help from their family only and the most likely to be supported by non-kin. They also exhibited the highest risk of dying in a nursing home. In Mediterranean countries, a pattern of exclusive family support and dying at home prevailed. The findings support the notion of a "mixed responsibility" of families and welfare states as providers of support for older people in the last year of life. (RH)

ISSN: 0144686X

From : <http://www.journals.cambridge.org/asodoi:10.1017/S0144686X10000280>

Learning and unlearning for end of life care in care homes; by Malcolm L Johnson. Leicester: Association for Education & Ageing - AEA, June 2010, pp 53-66.

International Journal of Education and Ageing, vol 1, no 1, June 2010, pp 53-66.

The long term care of older people around the world is largely in the hands of people with low levels of education and small amounts of training. Even nurses working in nursing homes often lack specific training. This paper presents the development, implementation and evaluation of a short training package on end of life care, delivered to staff of 106 residential / social care and nursing homes run by the largest not-for-profit provider in the UK. It, and a subsequent national study, show how strong the "embedded values" of enhanced personal care, skills in the relief of suffering and attention to the need for empathic human presence are played out. The findings also provide detailed evidence of support and facilities for relatives as they seek to spend time in the last days and hours. It is concluded that enhancing and validating the positive values and practices with short training is more desirable than turning end of life care into a specialist field of work with its own credentials. (RH)

ISSN: 20445458

From : Institute of Lifelong Learning, Leicester University, Regent Road, Leicester, LE1 7AA.

Managing sudden death in hospital; by Paul J Frost, Stephen Leadbeatter, Matt P Wise.

British Medical Journal, vol 340, no 7754, 8 May 2010, pp 1024-1028.

Junior doctors play an important role in verifying sudden deaths in hospital and communicating with the family of the deceased. This article includes some case scenarios illustrative of how best to manage a sudden death; the circumstances in which a death should be referred to the coroner; and the questions to be considered in completing a medical certificate of cause of death. The authors comment that while the Liverpool care pathway generally provides a framework for managing end of life care, it cannot be used fully for unexpected hospital deaths. The broader point of this article is that junior doctors have reported insufficient training in how to break bad news; and that even more experienced clinicians are not always confident in their ability to inform families of a sudden death. This article covers England and Wales; the situation in Northern Ireland differs in some respects. (RH)

ISSN: 09598138

From : www.bmj.com/doi:10.1136/bmj.c962

The missing piece: meeting people's spiritual needs in end of life care; by Simon Chapman, National Council for Palliative Care - NCP. London: National Council for Palliative Care, 2010, 20 pp.

The 'End of life care strategy' (Department of Health 2008) confirmed that provision for the spiritual needs of the dying required further work to develop practice. This National Council for Palliative Care (NCP) report explores the key themes highlighted at "The Missing Piece" conference held in March 2010. It defines five different context within which spirituality can be expressed - religious, self-spirituality, aesthetic, secular, and therapeutic - as well as as there being different dimensions of spiritual need. It discusses spiritual support in different settings, and suggests that staff training and development is a priority. The document is also intended to promote discussion on the subject, on which examples of good practice are sought. Appendices include the competencies from the NICE guidance, 'Spiritual and religious care competencies for specialist palliative care'; and draft quality markers for spiritual support, on which the Department of Health (DH) is to consult in Autumn 2010. (RH)

ISBN: 1898915850

Price: £10.00 (free to 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

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 - NCP. 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 NCP) 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 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

Notes on the end of life: the social interactions between patients, carers and professionals; by Daniel Briggs.

Quality in Ageing and Older Adults, vol 11, issue 2, June 2010, pp 35-46.

How people die and experience the road to death is important for all concerned: the patient who is dying, the family carers and loved ones they leave behind, and the health and social care practitioners. However, family carers often make great emotional and financial sacrifices and also assume heavy administrative roles to support the care of their loved one. This paper reports on the social interactions between patients, carers and professionals during end of life (EOL) care. The findings are based on a primary care trust (PCT) funded consultation that examined the quality of EOL care services in one London borough. The project made great use of ethnographic methods (open-ended qualitative interviews and observations) with 50 borough residents, of whom 32 were patients and 18 were carers. The findings consider in more detail the social relationships between patients, carers and professionals. It is suggested that while there are some encouraging signs of good practice among EOL agencies and professionals, greater care is needed on the part of frontline professionals in their day-to-day interaction with patients and carers to ensure a better quality of EOL care. (RH)

ISSN: 14717794

From : Website: <http://www.pierprofessional.com>doi: 10.5042/qiaoa.2010.0288

The oldest old and GP end-of-life care in the Dutch community: a nationwide study; by Ebus Abarshi, Michael A Echteld, Lieve Van den Block (et al).

Age and Ageing, vol 39, no 6, November 2010, pp 716-722.

Provision of adequate care for the oldest old is increasingly crucial, given the current ageing trends. This study explores differences in end-of-life care of the oldest (85+ years) versus the younger (65-84 years) old; testing the hypothesis that age could be an independent correlate of receiving specialised palliative care services (SPCS), having palliative-centred treatment and dying in a preferred place. General practitioners (GPs) participating in the nation-wide representative network in the Netherlands were asked to fill in patient, illness and care characteristics of all registered patients ≥ 65 years, who died non-suddenly in their practices between 2005 and 2008, using standardised forms. Associations with the palliative care variables were tested using multiple logistic regression. Results: nine hundred and ninety patients were registered. Among the oldest old, there were more women than men, more patients with heart failure than cancer, less hospital and home deaths and more residential care home deaths compared with the younger old. Of the oldest old, fewer received SPCS and more preferred to die in a residential care home than the younger old. Age was independently associated with palliative care provided: compared with the younger group, the oldest old received SPCS less often (OR = 0.7) and were treated with a palliative-centred goal more often (OR = 2.4); but age was not related to dying in a preferred place, i.e. independent of other characteristics. This study shows age to be independently associated with receiving SPCS in the Dutch community. Although the GPs do recognise the 'palliative phase' in the oldest old, involvement of specialist teams is somewhat less. (KJ)

ISSN: 00020729

From : <http://www.ageing.oxfordjournals.org><http://www.bgs.org.uk>doi: 10.1093/ageing/afq097

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

Palliative role in dementia: [The Dementia Declaration]; by Vern Pitt.
Community Care, issue 1814, 15 April 2010, pp 26-27.

Continuing with Community Care's election campaign theme, the Dementia Declaration, this article looks at a pilot scheme by supported housing provider Housing 21. A specialist palliative nurse has been appointed to tackle the neglect of dementia patients' end-of-life needs at Housing 21's Dementia Voice nurse service run in partnership with Westminster City Council and the NHS. (RH)

ISSN: 03075508

From : www.communitycare.co.uk

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)

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From : [http://www.ingentaconnect.com/content/bsc/hsscDOI: 10.1111/j.1365-2524.2010.00933.x](http://www.ingentaconnect.com/content/bsc/hsscDOI:10.1111/j.1365-2524.2010.00933.x)

The quality of death: ranking end-of-life care across the world: a report from the Economist Intelligence Unit; commissioned by LIEN Foundation; by Sarah Murray, Economist Intelligence Unit - EIU. London: Economist Intelligence Unit, 2010, 39 pp.

The Lien Foundation, a philanthropic organisation in Singapore commissioned the Economist Intelligence Unit (EIU) to devise a "Quality of Death" Index to rank 40 countries according to their provision of end-of-life care. This report outlines the index methodology, overall rankings, and what constitutes a high or low quality of death. The report examines the cultural issues (e.g. attitudes to death and dying) and the economics (i.e. funding models) of end-of-life care. It covers policy issues in end-of-life care: the extent to which governments recognise the importance of palliative care; integration of care into mainstream services; and building capacity for home-based care. While the report finds that the UK leads the world in quality of death, the UK performs less well on indicators such as the basic end-of-life healthcare environment, cost of care and availability of pain killers (morphine and morphine equivalents). The author also conducted interviews with more than 20 experts worldwide - including palliative care specialists, physicians, healthcare economists and sociologists - to review existing research. A detailed examination of the Index findings and country scores is also available (see website www.qualityofdeath.org). (RH)

From : Download: http://www.gla.ac.uk/media/media_163283_en.pdf

Small is beautiful: involving people with personal experience; by National Council for Palliative Care - NCPC. London: National Council for Palliative Care, June 2010, 2 pp.

'Small is beautiful' is one of two documents about user involvement in end of life care. It demonstrates a very simple way of hearing about small things that make a great difference to people, and can be used in hospitals, care homes, hospices and other places of care. (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

Special SEDAP Section : Canada's vulnerable older populations; by Bruce Newbold, Kathi Wilson (eds), Social and Economic Dimensions of an Aging Population Project - SEDAP.

Canadian Journal on Aging, vol 29, no 3, September 2010, pp 307-398 (7 articles).

The multidisciplinary research programme Social and Economic Dimensions of an Aging Population (SEDAP-II) is concerned with how population ageing will affect Canada's labour force and economy. Seven articles in this issue of the Canadian Journal on Aging represent a cross-section of research into Canada's vulnerable older populations. The articles consider the health care system and the use of private care and specialised medical intervention; health differences and disparities among older vulnerable populations; and the related topics of housing, long-term care and end-of-life care. (RH)

ISSN: 07149808

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

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

Supporting persons with Down syndrome and advanced dementia: challenges and care concerns; by Mary McCarron, Philip McCallion, Elizabeth Fahey-McCarthy (et al).

Dementia: the international journal of social research and practice, vol 9, no 2, May 2010, pp 285-298.

The aim of this study was to understand staff perceptions of critical issues in caring for persons with intellectual disability (ID) and advanced dementia. There has been growing interest in addressing resource, training, and service redesign issues including an increase in collaborative practices in response to the growing incidence of dementia among persons with ID. Most recently, this has included consideration of the specific issues in advanced dementia. Thirteen focus group interviews were held involving staff in six ID services and one specialist palliative care provider in Ireland. A qualitative descriptive approach was taken to analysis. Staff identified three key themes: (1) readiness to respond to end of life needs, (2) the fear of swallowing difficulties, and (3) environmental concerns and ageing in place. Four underlying issues that emerged in this study offer clues to solutions: (a) differences in staff preparation associated with settings; (b) lack of understanding and lack of collaboration with palliative care services; (c) uncertainties about the ability to transfer existing palliative care models to persons with ID and dementia; and (d) the need to develop training on end stage dementia and related care approaches. (KJ/RH)

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From : <http://dem.sagepub.com/doi:10.1177/1471301209354025>

Terminally ill elders' anticipation of support in dying and in death; by Tracy A Schroepfer, Hyunjin Noh. Binghamton, NY: Haworth Social Work Practice Press, 2010, pp 73-90.

Journal of Social Work in End-of-life & Palliative Care, vol 6, nos 1/2, 2010, pp 73-90.

This study explored terminally ill older people's anticipation of future support, which may be particularly important due to their vulnerable state and resulting support needs. Qualitative data was gathered from face-to-face interviews with 100 older Americans receiving hospice care, 85 of whom discussed anticipating future support. Content analysis revealed that anticipating support was based on current experiences of received support, and that the definition of future extended beyond death for some who anticipated surviving loved ones receiving grief support. Not all anticipation of support evoked positive feelings. Some respondents anticipated receiving unhelpful support or felt guilty about anticipating support from overburdened caregivers. Implications are discussed regarding the role of social workers in working with caregivers to ensure that the terminally ill older people they care for can anticipate future support in their dying process and after death. (RH)

ISSN: 15524256

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

Ultimately personal: shaping services around people in end of life care; by National Council for Palliative Care - NCPC. London: National Council for Palliative Care, 2010, 28 pp.

This document is published as an immediate response to the new Government's early identification of personalisation and empowering people amongst its defining priorities. It was written in August 2010 and takes account of policy announcements made up to and including that date, in particular the Coalition's 'Programme for Government' and the White Paper 'Equity and excellence: liberating the NHS'. The National Council for Palliative Care (NCPC) intends to explore how end of life care can help build compassionate communities and support as part of the "Big Society". The document explains what the NCPC and the Dying Matters coalition will be doing to ensure that palliative and end of life care continues to be a key priority for decision-makers at every level. (RH)

ISBN: 1898915849

Price: £10.00 (free to 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

Variations in place of death in England: inequalities or appropriate consequences of age, gender and cause of death?; by Kate Ruth, Andrew Pring, Julia Verne, National End of Life Care Intelligence Network - NEOFICIN, NHS End of Life Programme, Department of Health - DH; South West Public Health Observatory - SWPHO. London: NHS End of Life Programme, Department of Health - DH, August 2010, 88 pp.

This report, the first in a series commissioned by the National End-of-Life Care Intelligence Network (NEoLCIN) and written by the South West Public Health Observatory, follows on from the launch of the Network's website (www.endoflifecare-intelligence.org.uk). It highlights variations in where people die and challenges current thinking about the appropriateness of different end of life care settings for different groups, depending on their age, sex and socioeconomic status. The report summarises the key features from the first tranche of national End of Life Care Profiles to provide the first comprehensive overview for England of variations in place of death by geography, demography and main cause of death. The report also includes some additional data not included in the profiles, for example analyses by deprivation quintile. Among key findings in an Executive Summary are that in 2007, there were 471,092 deaths in England, of which 52% (246,412) were females compared with 48% (224,680) males. This equates to about 1,300 deaths per day in England and about one death per minute. In comparison, there were 672,809 live births in 2008 in England which equates to about 1,843 births per day and about 1.3 births per minute. (KJ/RH)

Price: download

From : Download from: <http://www.endoflifecare-intelligence.org.uk/resources/publications/default.aspx#neolcin> (Author contact: South West Public Health Observatory, Grosvenor House, 149 Whiteladies Road, Bristol BS8 2RA.)