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- Palliative Care

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*Regular Reads is a supplement of mosAIC, the Agency for Integrated Care’s publication for the Community Care sector. Filled with information such as programmes, good practices, book and journal summaries as well as stories from the sector, mosAIC is available free for Community Care staff. For more information, visit http://www.aic.sg/mosaic
# Table of Contents

- Blended e-learning and end of life care in nursing homes: A small-scale mixed methods case study  
  pg 4
- One chance to get it right: Improving people’s experience of care in the last few days and hours of life  
  pg 4
- Critical end-of-life communication  
  pg 5
- Global atlas of palliative care at the end of life  
  pg 5
- Intervention to improve care at life’s end in inpatient settings: The BEACON trial  
  pg 5
- Quality of dying in nursing home residents dying with dementia: Does advanced care planning matter? A nationwide postmortem study  
  pg 6
- Pediatric palliative care: A reflection on terminology  
  pg 6
- Integrating palliative care into nursing homes: Challenges and opportunities  
  pg 6
- Transitions to hospice care – Social workers foster meaningful conversations about dying  
  pg 7
- A qualitative study examining the sustainability of shared care in the delivery of palliative care services in the community  
  pg 7
- Advance planning for quality care at end of life – Action plan 2013-2018  
  pg 7
- Family members’ perceptions of end-of-life care across diverse locations of care  
  pg 8
- “People’s final journey must be one of their choosing...”: Ways and means  
  pg 8
- Clinical practice guidelines for quality palliative care (Third edition)  
  pg 8
- Frailty in older adults: Implications for end-of-life care  
  pg 8
- Palliative care services: Solutions for better patient care and today’s health care delivery challenges  
  pg 9
- Next generation of palliative care: Community models offer services outside the hospital  
  pg 9
- The perspectives of bereaved family carers on dying at home: The study protocol of “Unpacking the home: Family carers” reflections on dying at home  
  pg 9
- Older patients’ attitudes towards and experiences of patient-physician end-of-life communication: A secondary analysis  
  A secondary analysis of interviews from British, Dutch and Belgian patients  
  pg 10
- End of life care facilitator competency framework  
  pg 10
- Clinical aspects of palliative care in advanced Parkinson’s disease  
  pg 10
- Commissioning personcentred end of life care: A toolkit for health and social care professionals  
  pg 11
- In-home palliative care allows more patients to die at home, leading to higher satisfaction and lower acute care utilization and costs  
  pg 11
- Understanding patterns of health and social care at the end of life  
  pg 11
- After you: Conversations between patients and healthcare professionals in planning for end of life care  
  pg 11
- Under-diagnosis of pain by primary physicians and late referral to a palliative care team  
  pg 12
- What do we know now that we didn’t know a year ago? New intelligence on end of life care in England  
  pg 12
- Advanced care planning in care homes for older people: A qualitative study of the views of care staff and families  
  pg 12

All links were last checked in April 2016.

mosAIC | Regular Reads | http://www.aic.sg/mosaic/regular-reads
The fundamentals of hospice compliance: What is it and what are the implications for the future? An overview for hospice clinicians, part 1

End-of-life care in Germany: Study design, methods and first results of the EPACS study (Establishment of Hospice and Palliative Care Services in Germany)

Environments designed to heal
mosAIC’s Regular Reads aims to give relevant, useful information to Community Care partners for the improvement of their operations. This section features journal articles that highlight latest research findings as well as good, evidence-based and innovative practices. While the articles aim to keep Community Care partners informed of current developments in the sector, the views and opinions expressed or implied do not necessarily reflect those of AIC, its directors or editorial staff.

**Blended e-learning and end of life care in nursing homes: A small-scale mixed methods case study**

A blended training course that comprised e-learning and facilitated workshops for staff that had relatively infrequent contact with end-of-life care was delivered across several counties in England. The aim was to improve end-of-life care in nursing and residential care homes. This study examines the impact of the course. It found that there were improvements in participants’ confidence in delivering end-of-life care, particularly in the core competency areas of symptom management, communication and advance care planning. Participants had a more holistic understanding of end-of-life care. The barriers in changes to practice encountered were uneven participation; the absence of mechanisms for disseminating new insights and knowledge within the home; and a widespread perception that nurses’ professional dominance in the home made sustainable change difficult to enact.


**One chance to get it right: Improving people’s experience of care in the last few days and hours of life**

This report presents the approach to care for dying people that should be adopted by hospitals, hospices, homes and during transfers between different settings in England. It outlines five priority areas for care when it is thought that a person may die within the next few days or hours. They include: the possibility of a person dying is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes are regularly reviewed; sensitive communication takes place between staff, the dying person and people important to them; the dying person and those identified as important to them are involved in decisions about treatment and care to the extent that the dying person wants; the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible; and an individual plan of care that includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.


Key in “Leadership Alliance for the Care of Dying People” under “Contains” / Select “Liverpool Care Pathway review: response to recommendations”
Critical end-of-life communication

This article highlights that comprehensive, timely and person-centred communication is important when providing older adults and their caregivers, especially those with life-limiting illness, with end-of-life care. The diagnostic procedures and complex treatments in end-stage illness – which may extend to appointment scheduling, transportation, side effects, additional medications, aftercare, recovery time and out-of-pocket expenses – may be painful and futile to the older adults. Hence, practitioners should be more judicious in treating them. They should exchange key information; spend time getting to know the person; engage in relational communication; allow patients and their families to participate in decision making and ascertain the meaning behind patients’ and their families’ behaviours.


Search for the full-text article at www.todaysgeriatricmedicine.com

Global atlas of palliative care at the end of life

This report documents the need for and availability of palliative care globally. It uses maps, graphs and case studies to address the meaning of palliative care; why it is a human rights issue; the main diseases requiring palliative care; the need for palliative care; and where is palliative care currently available. It examines the main barriers and response to palliative care development. It details the models of palliative care worldwide including case studies from India, Tanzania, Romania, USA, Vietnam, Argentina and England. The resources that are devoted to palliative care that include financial resources, philanthropic and bilateral support, research support and educational resources are outlined. The report concludes by looking at the way forward for advanced palliative care.


Search for the full-text article at www.who.int

Intervention to improve care at life’s end in inpatient settings: The BEACON trial

This study evaluates the effectiveness of a multi-modal intervention strategy to improve processes of end-of-life care in inpatient settings. Staff training was targeted at all hospital providers. Dying patients were actively identified and best practices from home-based hospice care were implemented. Several processes of care were identified as quality endpoints for end-of-life care. Primary endpoints were an order for opioid pain medication at the time of death; do-not-resuscitate order; location of death; nasogastric tube; intravenous line infusing; and physical restraint. Secondary endpoints were administration of opioids, order/administration of antipsychotics, benzodiazepines, and scopolamine (for death rattle); sublingual administration; advance directives; palliative care consultations; and pastoral care services. This broadly targeted intervention led to modest but statistically significant changes in several processes of care.


Search for the full-text article at http://link.springer.com
Quality of dying in nursing home residents dying with dementia: Does advanced care planning matter? A nationwide postmortem study

A crucial component of good quality palliative care is advanced care planning, especially for people who lose the capacity to make decisions at the end of life such as nursing home residents with dementia. This study investigates the extent to which written advance patient directives and verbal communication with patients and relatives about future care, and written advanced general practitioner orders are related to the quality of dying of nursing home residents with dementia. It analysed 101 deaths of residents with dementia in 69 nursing homes in Belgium. It found a strong association between having a written advanced directive and quality of dying. When wishes were written, relatives reported a lower level of emotional distress at the end of life.


Search for the full-text article at www.plosone.org

Pediatric palliative care: A reflection on terminology

The term “palliative care” is not a very familiar one. A survey involving 1,600 interviewees revealed that only about 50 per cent have ever heard of the term. A survey involving another set of 50 interviewees found that the most favoured notion was that palliative care allows the best possible quality of life to the last, despite severe illness, as it conveys a sense of hope and emotional security. The least favoured were the ones stating that palliative care means accepting dying and living to the end. Hence, this review discusses current definitions as well as efforts to overcome their weaknesses and make the term palliative care–for both children and adults–more intelligible.


Search for the full-text article at www.la-press.com

Integrating palliative care into nursing homes: Challenges and opportunities

An increasing number of Americans are dying in nursing homes each year. However, substantial barriers continue to impede the meaningful integration of palliative and hospice care into the long-term services received by residents. These barriers include the regulatory standards governing nursing homes, and fragmented approach of Medicare and Medicaid in financing acute, post-acute, palliative and supportive services. This article explores three emerging models of delivering palliative care in nursing homes: hospice agency and nursing home partnership; externally based palliative care; and facility-based palliative care. While these models hold great promise for enhancing long-term care, there needs to be additional policy changes to integrate palliative care services more fully into nursing homes. The article provides three recommendations for policy change.


Search for the full-text article at healthaffairs.org/blog
Transitions to hospice care – Social workers foster meaningful conversations about dying

While transitions to hospice care are increasing, it happens much later, usually in the last three days of life after increasing numbers of intensive care stays and multiple hospitalisations. This shortens the period of palliative services offered to minimise suffering, improve quality of life and prepare the patient and family for death. Interdisciplinary teams have no opportunity to work on biopsychosocial and spiritual issues. Social workers play a key role in promoting timely access to hospice as they are most involved in patient communication, decision making and hospice care referral. Their most important role is to understand the choices made by the patients and their families, encourage an open communication about how the patients wish to spend the last days of their lives and help them move in that direction.


Search for the full-text article at www.socialworktoday.com

A qualitative study examining the sustainability of shared care in the delivery of palliative care services in the community

This paper examines the sustainability of existing palliative care teams that provide home-based care using a shared care model in Ontario, Canada. It explores factors that affect the sustainability of the teams at the community, regional (local health integration network or LHINs), and the province level. It found that these three scales are connected. Integration and collaboration within and between scales is necessary to achieve sustainability. It provides recommendations for stakeholders in each scale to contribute to sustainable palliative care teams.


Search for the full-text article at www.biomedcentral.com

Advance planning for quality care at end of life – Action plan 2013-2018

This action plan guides the New South Wales health authorities’ implementation of advance care planning over the next five years. It identifies strategic partnerships with other government agencies and sectors to improve their planning for end-of-life care in primary, acute and aged care settings. In addition, the plan aims to “normalise” Advance Care Planning and improve end-of-life care by integrating patients’ wishes into the management of chronic life-limiting illnesses. It seeks to ensure that patients are provided with care consistent with their wishes, within therapeutic limits, and always focused on quality symptom management and best practice. It lists six outcomes for the way forward, including ensuring that patients’ wishes are appropriately documented and understood by health professionals who treat them, and ensuring that “families and carers are clear about the wishes of patients in advance so that they experience reduced burden of decision-making on the patient’s behalf”.


Search for the full-text article at www.health.nsw.gov.au
Family members’ perceptions of end-of-life care across diverse locations of care

This study assessed the perceived level of satisfaction with end-of-life care by family members, especially during the last 48 hours of life. This was done via a telephone survey with bereaved family members of patients who died in a health care organisation in British Columbia, Canada. It was found that family members of the bereaved felt they were not sufficiently informed about a number of issues regarding the patient, such as the patient’s changing condition and what to do at the time of death. The bereaved family also felt that their loved ones lacked emotional support and their own emotional needs were also not met adequately. This was particularly the case in acute care and residential care institutions. Hospices had the fewest unmet needs, followed by palliative and intensive care units.


Search for the full-text article at www.biomedcentral.com

“People’s final journey must be one of their choosing...”: Ways and means

This report explores the importance of personalisation in all aspects of care and the difficulties ensuring that personalised care is offered in all settings. It explores challenges and barriers that prevent people from being able to make choices about the kind of end-of-life care that they receive. It argues that emphasis should be placed on training, communication and integration across health and social care to address the inequalities in care. It recommends free social care at the end of life be adopted and that health and care professionals are equipped and properly supported to talk about death.


Search for the full-text article at www.demos.co.uk

Clinical practice guidelines for quality palliative care (Third edition)

This report provides clinical practice guidelines created by the National Consensus Project for Quality Palliative Care to improve the quality of care in the United States. This guideline promotes quality palliative care, fosters consistent and high standard in palliative care and encourages continuity of care across settings. It covers structure and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious and existential aspects of care; cultural aspects of care; care of the patient at the end of life; and ethical and legal aspects of care.


Search for the full-text article at www.nationalconsensusproject.org

Frailty in older adults: Implications for end-of-life care

This report examines the important implications frailty in older adults has on their care needs and how those needs are met. Frail older adults are more susceptible to delirium, functional decline, impaired mobility, falls, social withdrawal and death. By assessing their medical conditions, cognition, function, mobility, balance and social circumstance, clinicians can better engage patients and their family in difficult discussions about treatment plans and prognosis and deliver better palliative care.

Search for the full-text article at www.ccjm.org

Palliative care services: Solutions for better patient care and today's health care delivery challenges

This report looks at the benefits of providing high quality palliative care services and highlights how several healthcare systems in the United States have created palliative care programmes that are achieving successful outcomes and improving quality of care by reducing admissions, using resources wisely and integrating systems. It describes how palliative care services are delivered via the following channels: consultation service; inpatient units; integration into the intensive care unit and the emergency department; and outpatient care. The report also provides case examples and outlines the steps to start or expand palliative care services.


Search for the full-text article at www.hpoe.org

Next generation of palliative care: Community models offer services outside the hospital

Community-based palliative care (CBPC) in the United States aims to provide palliative care services for patients outside of the acute hospital and regulatory and reimbursement structures of hospice care under Medicare. This report looks at the opportunities and challenges of CBPC and describes some of the emerging palliative care models. It also identifies developments that would promote CBPC and outlines 10 issues that organisations and providers will need to consider. The issues include: clarification of goals; operating model; business model; interdisciplinary team; palliative care expertise; access to patients; organisational culture; alignment with healthcare reform; standard of practice; and a clear message for various audiences and constituencies.


Search for the full-text article at www.chcf.org

The perspectives of bereaved family carers on dying at home: The study protocol of “Unpacking the home: Family carers” reflections on dying at home

Through the accounts of bereaved family members, the “Unpacking the home” study aims to gain an in-depth understanding of “home” and the issues faced by family members caring for a dying older person at home. This study protocol also seeks to examine the way the home is transformed in the process of providing end-of-life care, and offers a critical analysis of policies that aim to increase home deaths. In-depth interviews will be conducted in the north and south of England with 50 bereaved family carers to elicit their accounts of witnessing the dying in the home of an older person (50+ years). This study seeks to make recommendations that will ensure that family carers receive appropriate and adequate support in caring for their loved ones at the end of life.


Search for the full-text article at www.biomedcentral.com
Older patients’ attitudes towards and experiences of patient-physician end-of-life communication: A secondary analysis of interviews from British, Dutch and Belgian patients

This study examines older patients’ attitudes towards and experiences of, patient-physician end-of-life (EoL) communication in three European countries. A secondary analysis of interviews from British, Dutch and Belgian patients over the age of 60 with a progressive terminal illness was conducted. Confidence and trust were reinforced by physicians’ availability, time and genuine attention and hindered by misdiagnoses and poor communication style. Most participants preferred full disclosure, though some wished to be deliberately ill-informed to avoid distress. Patients expressed a variety of preferences for and experiences of involvement in medical EoL decision-making and a few complained that information was only provided about the physician’s preferred treatment.


Search for the full-text article at www.biomedcentral.com

End of life care facilitator competency framework

The framework is designed to support the development of End of Life Care Facilitators by identifying the extent of knowledge and skill required for that level of practitioner. It recognises that to be effective, practitioners must be competent to fulfil the functions of their role. In addition, it is essential that facilitators expand their area of competence by developing the breadth and depth of their knowledge, and their skill and expertise. It sets out key components for the following core competency areas: communication, facilitation, audit; and learning and development. It includes a template to negotiate a learning and development plan, as well as a template to undertake reflective practice based on the competency framework.


Access the full-text article at www.nhsiq.nhs.uk/media/2361601/eolc_facilitators_competency_framework_form.pdf

Clinical aspects of palliative care in advanced Parkinson’s disease

Parkinson’s disease (PD) is one of the most common neurodegenerative disorders of the elderly population. This review seeks to provide a short summary of some of the palliative care issues of end-stage PD from a clinical and pragmatic point of view and discusses how patients can be treated through the application of common principles of palliative care management. References for this review were selected through a search in PubMed for potentially relevant articles with the search terms of “Parkinson’s disease”, “palliative care”, and “advanced Parkinson’s disease”. The review focuses on the medical management of motor and non-motor manifestations and concentrates on end-stage PD patients.


Search for the full-text article at www.biomedcentral.com
Commissioning person centred end of life care: A toolkit for health and social care professionals

Personalised, integrated care at the end of life can transform that experience for the individual, their family and the staff caring for them. Commissioning high quality end-of-life care presents particular challenges because of the need to coordinate and integrate the wide range of services involved across health and social care. To help achieve a “good death” for all, this interactive guide identifies the main elements involved in commissioning end-of-life care services, explains the commissioning cycle in practical terms and offers a four-stage approach across all sectors. The four stages are: analysing and planning; designing pathways; specifying and procuring; and delivering and improving.


Search for the full-text article at http://socialwelfare.bl.uk/index.aspx

In-home palliative care allows more patients to die at home, leading to higher satisfaction and lower acute care utilization and costs

This report details a home-based model of palliative care that was developed using an interdisciplinary team of providers, to manage symptoms and pain, provide emotional and spiritual support, and educate patients and family members on an ongoing basis about changes in the patient's condition. One randomised controlled trial (RCT) and one comparison-group study showed that the programme increased patient satisfaction; increased the portion of patients dying at home rather than in the hospital; and reduced emergency department visits, inpatient admissions and costs.


Search for the full-text article at https://innovations.ahrq.gov

Understanding patterns of health and social care at the end of life

This study describes the uptake of key health and social care services for people in the last 12 months of life in the United Kingdom. It found that there were considerable variation in the use of social care between local authorities; many more people used hospital care than social care in the last year of life (89.6 per cent versus 27.8 per cent); and total hospital costs in this period were approximately double those of social care services. Individuals in the last 12 months of their lives were significantly more likely to use a social care service than similar individuals in the general population. Individuals with the highest social care costs had relatively low average hospital costs.


Search for the full-text article at www.nuffieldtrust.org.uk

After you: Conversations between patients and healthcare professionals in planning for end of life care

This study provides insights into the complexities surrounding the initiation of Advance Care Planning involving conversations about end of life care preferences with patients who are identified as having palliative care needs. It adopted an exploratory
case study design using qualitative interviews across five services delivering palliative care to cancer and non-cancer patients within an urban and rural English region. The study found that patients demonstrated varying degrees of reticence, evasion or reluctance to initiate any conversations about end of life care preferences. Most assumed that staff would initiate such conversations, while staff were often hesitant to do so.


Search for the full-text article at www.biomedcentral.com

Under-diagnosis of pain by primary physicians and late referral to a palliative care team

The under-diagnosis of pain constitutes a serious problem in cancer care. The study examines the association between late referral to a Palliative Care Team (PCT) after admission and the under-diagnosis of pain by primary physicians. The study was carried out in the Teikyo University teaching-hospital in Japan for a period of 20 months and investigates triads composed of 213 adult cancer inpatients who had coexisting moderate or severe pain at the initial PCT consultation, 77 primary physicians, and four palliative care physicians. The results revealed that under-diagnosis of pain by primary physicians was associated with late referral to PCTs. Shortening the duration from admission to referral to PCTs, and increasing physicians’ awareness of palliative care may improve pain management for cancer patients.


Search for the full-text article at www.biomedcentral.com

What do we know now that we didn’t know a year ago? New intelligence on end of life care in England

The report highlights the key findings from research and analysis carried out by the National End of Life Care Intelligence Network over the last year on end-of-life care in England. The report looks at the care people received in their last year or months of life. Topics covered include: Preferences of place of care and place of death; inpatient hospital care; social care; primary care; care homes; specialist palliative care; different disease groups; costs of care; workforce, competencies; and training; and quality of care.


Search for the full-text article at www.endoflifecare-intelligence.org.uk

Advanced care planning in care homes for older people: A qualitative study of the views of care staff and families

The aim of this study was to explore views on advance care planning (ACP) in care homes for older people. The study undertook a qualitative exploration of views from care home staff and the family of residents in care homes for older people in all care homes for the elderly in two London Boroughs. Staff (care managers, nurses and care assistants), community nurses and families participated in the study comprising individual semi-structured interviews. The results revealed that staff and family voiced positive opinions towards advance care planning. Staff felt that it provided choice for residents and encouraged better planning.
However, staff and families perceived residents as reluctant to discuss advance care planning. Some care assistants were reluctant to be involved.


Search for the full-text article at http://ageing.oxfordjournals.org

The fundamentals of hospice compliance: What is it and what are the implications for the future? An overview for hospice clinicians, part 1

Part 1 of this article provides an overview of the current Medicare compliance climate in the United States and outlines the implications for hospice providers. It explores the seven areas of a comprehensive compliance framework outlined in the 1999 Compliance Guidance for Hospices by the Health and Human Services Office of the Inspector General. These include implementing written policies, procedures and standards of conduct; designating a compliance officer and committee; conducting effective training and education; developing effective lines of communication; enforcing standards through well-publicised disciplinary guidelines; conducting internal monitoring and auditing; and responding promptly to detected offenses and developing corrective action. The article also provides a case example to set the stage for Part 2 of the article that explores hospice-specific risk areas and specific risk-reduction strategies.


Search for the full-text article at http://journals.lww.com

End-of-life care in Germany: Study design, methods and first results of the EPACS study (Establishment of Hospice and Palliative Care Services in Germany)

The EPACS study documents the quality of inpatient and outpatient end-of-life care before the structural changes to the outpatient sector were introduced in 2007. The study surveys 5000 deceased persons of Rhineland-Palatinate in Germany to understand the need for specialised outpatient care and the actual utilisation of these services. It found that nurses received a higher rating than physicians especially where the physicians’ communicative and emotional supporting skills were concerned. Another finding was that while 90 per cent of patients suffering from an incurable disease received professional home care, only 8.5 per cent of them were supported by specialist palliative care nurses. Hence, there was a gap between patients’ needs and services provided.


Search for the full text article at www.biomedcentral.com

Environments designed to heal

Enhancing the Healing Environment programme has funded projects to renovate the end-of-life care facilities of patients with dementia. This article explores how these various projects improved patient care by improving the care environment. It looks at creating a peaceful space for palliative care patients and their relatives by incorporating features like stained glass windows to enhance lighting and installation of local artwork. It talks about the process of consultation with carers and the patients to know...
their preferences and generating funds by publicity on radio stations and display boards. Creating a homely rather than institutional ambience is expected to improve the patients’ health by reducing their anxiety and risk.


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