Welcome to the May edition of @CARESEARCH.

This week palliAGED, a CareSearch product providing evidence-based guidance on palliative care for the aged care sector, turns two. To celebrate we feature a blog from CareSearch on the importance of evidence-based resources for the aged care sector and a blog on the role of evidence in quality improvement. We also highlight the soon to be launched Flinders University Centre for Death, Dying, and Palliative Care which is set to provide new insights into Australian attitudes and needs. Read on to find out more about this and other news including the latest research and community happenings.

NEWS FROM CARESEARCH

A New Research Centre for Palliative Care, Death and Dying

Led by Professor Jennifer Tieman, CareSearch Director and Matthew Flinders Fellow of the College of Nursing and Health Sciences Flinders University, a new Research Centre for Palliative Care, Death and Dying will be launched tomorrow. This Research Centre addresses palliative care, death and dying across the life course, across the community and across the health system. The research aims to:

- Builds an understanding of death, dying and palliative care in contemporary Australia
- Gives voice to the support and care needs of those who are dying, caring, or grieving through research and communication
- Supports access and use of palliative care evidence by health professionals and care providers
- Facilitates awareness among families, communities and society that death and dying is a part of life.

Engagement Project Update

In May the Engagement project team welcomed Robyn Dutschke to the team as the new lead researcher for the Patients, Carers and Families, arm of the project. Robyn takes over from Dr Lauren Miller-Lewis who has taken up a teaching position with Central Queensland University. Recent articles from the team include an article published in Australian Ageing Agenda (April 2019): Enabling Choices (147kb pdf) by Rosie Bonnin, and an article published in InMotion magazine (April 2019), Australian Physiotherapy Association: Tools to help physios in palliative care by Susan Gravier.

You can also view the Action Plans, keep up to date with all of the project outcomes, and provide any other feedback by visiting the Engagement Project webpage at CareSearch.

CareSearch is funded by the Australian Government Department of Health.
NEWS FROM THE WEBSITE

CareSearch Blog: Palliative Perspectives

**Why quality in palliative care guidance for aged care matters**
A blog post from Professor Jennifer Tieman, CareSearch Director, College of Nursing and Health Sciences, Flinders University

**Quality improvement – What now?**
A blog post from Professor Jennifer Tieman, CareSearch Director and Dr Katrina Erny-Albrecht, Senior Research Fellow, CareSearch, College of Nursing and Health Sciences, Flinders University

**Federal Budget brings new opportunities for Primary Care Nurses**
A guest blog post by Katharine Silk, Integration and Innovation Manager, Australian Healthcare and Hospitals Association (AHHA)

**Trajectories of functional decline at the end of life. What do they tell us?**
A guest blog post by Dr Deidre Morgan, Lecturer and Researcher, Palliative and Supportive Services, College of Nursing and Health Sciences, Flinders University

See More Palliative Perspectives Blogs
CareSearch Review Collection

34 systematic reviews were added to the CareSearch Review Collection since the last newsletter. They included:


  Based on 56 articles reporting on mostly small cohorts, this review examined the transition of people with advanced illness into the last phase of life from the perspectives of patient and family. The critical point prior to transition to comfort or palliative care was that of ‘realising terminality’. Transition was highly dependent on patients, family and health professionals having a shared understanding. For some this was followed by a ‘reframing’ phase where views of the situation altered the goals and factors of importance. Outcomes of the review strongly backed the contention that supporting people to transition from cure-focused care to palliative care with its focus on quality of life and comfort requires understandable information, support and respect for personhood, and support to maintain some level of control. Patient opportunity to exercise control and make choices positively impacted on anxiety, and nurses were found to be key providers of information. This information needed to be clear, consistent, and relevant to understanding prognosis, goals, and probable quality of life. However, often there was a broad lack of understanding of palliative care among patients and their families, as well as among care providers who often saw their role as focused on cure. Barriers to transition including physician resistance and family conflict, and implications for clinical practice, research and education are discussed.

  See more reviews on Transitions


  Based on 16 articles this review examined the feeling of being a burden among patients with advanced illness who had expressed a wish to hasten death (WTHD). Based on analysis of themes two dimensions were applied to describe feelings: personal and social. In the personal dimension dependence and loss of functionality (loss of ability to perform activities of daily living) impacted on self-perception of being a burden and a person’s loss of self-dignity. Themes of self-blame (responsibility for their own illness) or self-concept (emerging illness-based identity constructed by the patient) were also reported. The authors suggest ‘loss of perceived dignity’ as a useful category to group these losses in relation to
the emotional impact. In the social dimension loss of family role, societal role, being treated like an object, lack of respect for their decisions, needing help and making loved ones suffer were dominant themes related to self-perception of being a burden. Based on this review, feeling that one is a burden to others is a primary trigger for WTHD with multiple root causes some of which might be addressed following thorough clinical assessment. The findings presented provide important insights to guide holistic examination of a person’s suffering and their reasons for WTHD.

See more reviews on Desire for hastened death


The aim of this study was to determine the following for off-label drug use in palliative care; prevalence, approaches in clinical practice, awareness and knowledge of health care professionals, availability of management strategies to support this. Off-label prescribing in this context often reflects both increased symptom burden and reduced capacity for oral route medications. Based on eight articles, this systematic review incorporated data from six countries including Australia and relating to almost three thousand records. Palliative care settings examined were mostly inpatient apart from one which was an at home care unit. According to the authors of this review palliative care off-label prescribing is common. The range of off-label prescription prevalence varied depending on the definition applied but varied between 4.5% and 65%. Most decisions for off-label prescribing were backed by evidence or published literature. National level data on off-label prescribing in palliative care were reported for three countries. Policies generally focused on obtaining informed consent and in Australia only 11% of Institutions had a policy on off-label use of drugs in palliative care. From individual studies, the most common indications for off-label prescribing were agitation/sedation and delirium. However, prescribing was also noted with dyspnoea, excessive secretions, pain, nausea/vomiting and anxiety. The most common drugs used off-label were also listed and included haloperidol, chlorpromazine and morphine. This review provides an important insight into palliative care practices around off-label prescribing. However, as it draws on studies from the past 20 years and there was considerable study heterogeneity generalisability of outcomes to current practice and specific settings is limited.

See more reviews on Prescribing issues

Pressure ulcers are often used as a surrogate marker for quality of care, being regarded as avoidable or preventable events. In people approaching the end of life organ failure is accepted as a pre-terminal event. However, debate continues as to whether skin failure should be included in this, although it is accepted that in people receiving palliative care ulcer healing is unlikely. The aim of this systematic review was to examine the evidence for an association between the development of pressure ulcers and the terminal phase of illness. Based on 12 articles reporting on approximately 63,000 patients cared for in inpatient and community settings the review reports on prevalence, incidence, risk factors and timeline for pressure ulcer development. Prevalence of pressure ulcers in palliative care ranged from almost 10% to 55%, and the average of 12.4% was almost 3-fold higher than previously reported for the broader population. The overall incidence of 11% was also higher than in general populations, although the type of pressure ulcer seen was similar. The most significant risk factors were poor physical activity, advancing age, length of stay and high Waterlow score (validated tool for risk of pressure ulcer formation). Based on synthesis of the literature the review examines the relationship between pressure ulcers and the complex circumstances of people receiving palliative care. The higher prevalence in all care settings compared to general patient cohorts suggests that the appropriateness of including palliative care patients in general reporting systems may need to be re-examined.

See more reviews on Skin and wound care

WHAT’S NEW IN THE COMMUNITY?

National Palliative Care Week 19-25 May 2019

National Palliative Care Week is an annual event held to raise awareness of end of life and palliative care issues in the Australian community. This year’s theme is ‘What matters most?’ The week is organised by Palliative Care Australia and supported by the Commonwealth Department of Health.

Have We under invested in Palliative Care?

On Wednesday May 1st, at an event held at the Bradley Forum, UNISA, Adelaide Professor Stephen Duckett of the Grattan Institute, Melbourne, outlined how we can improve policy and payment design to increase access to palliative care. The podcast of this event is now freely available.
Palliative Care Australia (PCA) position statement

Palliative Care Australia (PCA) has released a position statement, Sustainable access to prescription opioids for use in palliative care (458kb pdf), with endorsement from 12 other peak health organisations, to call for a ‘future-proof’ approach to ensure sustainable access to prescription opioids for Australians receiving palliative care. The statement warns of unintended consequence of increased government and regulatory restrictions surrounding non-cancer opioid prescribing to reduce the misuse and abuse of opioids within the wider community. Eight recommendations are made to address the needs of people with life-limiting illness.

NHMRC National Dementia Research

The NHMRC Dementia Research Institute has partnered with the National Ageing Research Institute (NARI) and key stakeholders to develop a Dementia Research Action Plan targeting Culturally and Linguistically Diverse (CALD) communities. Dementia is one of Australia’s most significant health challenges. However, CALD communities are often underrepresented in, and at times excluded from, dementia research and other areas of Australian health and medical research. To help inform the development of the action plan individuals and organisations are invited to complete a short survey.

UPCOMING CONFERENCES AND WORKSHOPS

Conferences:

- **Grampians Regional Palliative Care Conference**
  May 23-24
  Creswick, Victoria

- **NSW Palliative Care Volunteer Conference**
  June 3-4
  Blacktown, New South Wales

- **5th International Conference on Ageing in a Foreign Land**
  June 3-4
  Adelaide, South Australia

- **Cancer Nurses Society of Australia (CNSA) 22nd Annual Congress**
  June 20-22
  Melbourne, Victoria

See more Conferences
Workshops:

- **Neurological Conditions in Palliative Care**
  May 15
  Shenton Park, Western Australia

- **Dementia in Diverse groups Symposium - National Workshop Series**
  May 15-16
  Hindmarsh, South Australia

- **End of life realities...caring is hard**
  May 17
  Launceston, Tasmania

- **Understanding a Palliative Approach**
  May 20
  Shenton Park, Western Australia or by Video Conference

See more Workshops.

DISTRIBUTING THE NEWSLETTER

You can print this newsletter for yourself or for staff who do not have access to email. You are welcome to forward the @CARESEARCH newsletter to others that may be interested in finding best palliative care research and evidence.

Do not forget you can follow what is happening on Twitter.

**June 2019 Newsletter**

The next newsletter will be circulated in June 2019. If you have any item you would like to have considered for inclusion, please send details by the first Wednesday in June to caresearch@flinders.edu.au.