Welcome to the May edition of @CARESEARCH.

This month we welcome a new team member, highlight new additions to the CareSearch website, and summarise some of the latest evidence in end of life and palliative care.

NEWS FROM CARESEARCH

New staff @ CareSearch

We are delighted to welcome Susan Gravier to the role of the Research Associate (Allied Health) responsible for assisting with the Allied Health Engagement Project activities, and updating content on palliAGED and CareSearch. We look forward to Susan’s continuing contribution to our work and the palliative care community.

New publications @ CareSearch


CareSearch turns 10

Plans are currently underway for our anniversary - watch this space.

Engagement Project update - EOI submission closing dates

CareSearch’s call for expressions of interest for its new project ‘Building knowledge and awareness through sector engagement’ is still open but closing soon.

CareSearch understands that providing access to trustworthy information on end of life and palliative care is essential but not enough on its own. Informed decisions happen when the information is accessed. To improve the uptake of resources and our understanding of when and how these are used, CareSearch will partner with communities to better understand their needs and learn how to encourage greater use of the online resources.

CareSearch is inviting nominations and expressions of interests from three specific groups: Patients, Carers and Families; Aged Care; and Allied Health. If you know of anyone from these groups who can help, please submit an expression of interest form or nominate by sending an email to caresearch@flinders.edu.au before the following dates:

- Aged Care: May 15
- Allied Health: June 1
- Patients, Carers and Families: June 15
NEWS FROM THE WEBSITE

CareSearch Blog: Palliative Perspectives
This month highlighting advanced care planning and patient experience

- **Family member experiences of the sudden, unexpected death of a loved one in an emergency department setting.**
  Health care professionals agree that the quality of care provided in the emergency department for dying patients and their families is often not as good as it needs to be. Dr Tracy Giles of Flinders University explains how her research into the experiences of family members will help to identify what is working well already and areas of care that need improvement, and how you can become involved.

- **How palliative care is delivered is more important than where it is delivered!**
  The location of palliative care is important, but the Health Care Consumers’ Association (HCCA) believes that the quality of care people receive is the most important factor determining their overall satisfaction. Dr Sarah Spiller and Dr Kathryn Dwan from HCCA discuss how palliative care is delivered is more important than where it is delivered.

- **National Advance Care Planning Week sparks 100+ events**
  For the first time, Advance Care Planning Australia (ACPA) ran National Advance Care Planning Week (16 - 22 April). Linda Notle, Program Director for ACPA discusses the impact of the initiative and the response of both the public and health care sector.

- **Support for health professionals to know more about end-of-life law**
  One part of advance care planning that is often unseen is law. Yet law plays an important role in end-of-life care. Professor Ben White and Professor Lindy Willmott from Queensland University of Technology explains the legal aspects of planning for advance care and end of life, and how the Australian Centre for Health Law Research supports health professionals.

- **National Advance Care Planning Week**
  Discussing your values and preferences helps determine what would be important to your future health care. Linda Nolte, Program Director for Advance Care Planning Australia discusses National Advance Care Planning Week and the importance of the making our future preferences known.

CareSearch Review Collection
52 systematic reviews were added to the CareSearch Review Collection in April. They included:

Based on 57 quantitative and qualitative studies, and including more than thirteen thousand practitioners, this systematic review found that general practitioners and specialists routinely inform families but not patients of a dementia diagnosis. Meta-analysis indicated that approximately one third of GPs usually, regularly or always inform people of their diagnosis, compared to 48% of specialists. For communicating a diagnosis of dementia to the family the corresponding values were approximately 89% and 97% respectively. Lack of confidence in the diagnosis often made practitioners hesitant to inform patients and family, as did the perceived stigma surrounding a diagnosis of dementia, and a practitioner's own beliefs. While the decision to diagnose was found to be made on a case-by-case basis, further investigation and sharing of assessment results was more likely if patients raised concerns about symptoms. Only one intervention to improve communication about dementia was identified, and this was unsuccessful. The authors make a number of recommendations including the need to develop guidelines and address stigma surrounding dementia in the community.


This systematic review of 27 mostly high-quality studies reporting on automated and manual analysis of content from online cancer communities found gender and role differences in the content provided and sought by participants. The number of posts analysed varied between 200 and 1.5 million. Although male and female patients generally looked for informational and emotional support respectively, family and friends mostly looked for informational support irrespective of gender. Patients increasingly looked for informational support with poor prognosis. In addition to providing insights into the role of social media in meeting and identifying some of the needs of people with cancer and their families, this review also highlights the emerging role of automatic analysis of user-generated content to enhance understanding from a patient perspective.


Based on 43 articles, this systematic review reports prevalence rates for dyspnea in children with life-threatening and life-limiting complex chronic conditions. Prevalence ranged from 17% to 80%, and varied with diagnosis. Highest rates were reported in children with cancer and at the end of life. Eight different tools were used to measure dyspnea, and the report highlighted the limitations of self-report tools for young children with limited communication. In addition to the need for new tools, this analysis found a lack of evidence for the effectiveness of current treatment approaches. The authors state that this contrasts with the strong evidence base for opioid use in adults with advanced disease.

Continuous subcutaneous infusion (CSCI) is a commonly employed method of multiple drug administration in end of life care. The length of infusion time varies between countries, with some allowing infusions over a number of days. In the UK infusion is limited to 24 hours based on limited evidence on chemical and microbial safety data. This systematic review of published literature provides an update on current availability of this data. Based on 21 studies covering 32 combinations of 24 drugs, it was found that the drugs most frequently included in combinations were haloperidol, morphine sulphate, midazolam and dexamethasone. The most drugs included in a single combination was six. Detailed analysis is provided of the different combinations examined, however, in all cases insufficient evidence was available with respect to CSCI solution physical, chemical and microbiological stability over a period of 48 hours. Clinically significant chemical degradation was observed for the benzodiazepine Midazolam when stored at body temperature, but not at room temperature. Poor solubility of Midazolam was related to pH, and formation of a precipitate was readily observed in combination with the alkaline drug dexamethasone. This review provides an important update on what evidence is available, and highlights the importance of caution when combining medications. New studies of drug stability and safety when used in combination are required before longer infusion times can be supported.


This systematic review examines studies reporting outcomes of home support interventions for older people with dementia and/or their carers. Based on 70 mostly high-quality randomised controlled trial studies, a total of nine different intervention approaches are described. Seven interventions targeted carers, and included education, advice, behaviour management, emotional support, social support, and respite. The two studies targeting patients incorporated environmental modifications and care coordination. Studies were predominately from the US and UK settings. Despite considerable variation in approach taken, most studies reported at least one significant change in outcomes including everyday functioning, behaviour, cognition and delaying nursing/care home admission. Education/advice and behaviour management were the most common combination, and together led to improved wellbeing, and reduced carer burden and problem behaviour. The focus of this review on outcomes is important, and highlights strategies that might be employed elsewhere to provide effective support.
WHAT’S NEW IN THE COMMUNITY?

New Quality and Safety Commission for Aged Care
The Minister for Aged Care Ken Wyatt has announced the formation of a new Aged Care Quality and Safety Commission. The commission will bring together the functions of the Australian Aged Care Quality Agency, Aged Care Complaints Commissioner and aged care regulatory functions of the Department of Health under a single quality and safety commissioner. The Aged Care Quality and Safety Commission will enable unified, responsive regulation, compliance and complaints handling. A new taskforce within the Department of Health will oversee the reforms to ensure the new commission is in place by 1st January 2019.

ELDAC: Supporting quality care at the end of life
End of Life Directions for Aged Care (ELDAC) is a project funded by the Australian Government Department of Health to support quality care at the end of life. ELDAC is building capacity within and linkages between the health care sector and aged care industry by offering a set of five evidence-based toolkits to support palliative care in residential, home and primary care settings. It also provides access to a telephone and web-based navigation services to enable aged care workers, nurses and GPs find palliative care information and details about service providers. CareSearch is a proud partner in the ELDAC Consortium and palliAGED evidence and resources are used in the new website. Find out more: www.eldac.com.au.

The role of Death Doulas in end of life care
In 2016, the CareSearch Massive Open Online Course (MOOC) ‘Dying2Learn’ highlighted the emerging role of the ‘death doula’. Today many consumers are choosing to place trust in ‘death doulas’ who can advocate for them or fill the gaps in meeting their end of life and palliative care needs. This emerging role and its contribution to end of life models of care has not been widely published in academic literature. Deb Rawlings and a team of researchers at Flinders University are addressing this information gap by conducting a survey of palliative care nurses who are aware of patients and families receiving support/guidance/care from a death doula or similar support person. Access the survey and learn more about this research supported by the CareSearch Research Data Management System (RDMS) for survey-based research.

National Seniors Australia report on consumer experiences of aged at home
In April 2018, National Seniors Australia released their report Accentuating the positive: Consumer experiences of aged care at home (613kb pdf) which was commissioned by the Australian Government Department of Health. Based on responses from 4,536 people aged 50 years and over, the survey contributes important insights into the care received and its impact on both recipients and their carers.
Integrated Carer Support Service

The Integrated Carer Support Service announced in March 2018, will provide carers with access to new early intervention supports and services to improve carers’ well-being and long term outcomes.

The new services are to be implemented in two stages:

- From October 2018, new digital services for carers will be rolled out through the CareGateway website including peer support, counselling, coaching and educational resources.
- From September 2019, a new network of Regional Delivery Partners will be established across Australia.

Consultation

The Department of Social Services is conducting an online consultation seeking feedback from the sector on proposed options for ICSS regional delivery model.

The consultation period will be open for submissions in response to the discussion paper, from Monday 9 April and will close on Friday 11 May 2018.

National Palliative Care Week

National Palliative Care Week is an annual awareness raising week organised by Palliative Care Australia.

The theme for this year’s National Palliative Care Week is ‘What matters most?’ and it will be held 20-26 May 2018. Visit Palliative Care Australia to find out more and access freely available communications material for you to use to promote National Palliative Care week.

UPCOMING CONFERENCES, SHORT COURSES AND EVENTS

Conferences:

- [Palliative Care Nurses Australia 2018 Biennial Conference](#)
  May 20-21
  Brisbane, Queensland
- [2018 Choosing Wisely Australia National Meeting](#)
  May 30
  Canberra, Australian Capital Territory
- [National Medicines Symposium 2018](#)
  May 30-June 1
  Canberra, Australian Capital Territory
- [Perth Satellite event - Death Literacy Conference](#)
  June 1
  Perth, Western Australia

See [more conferences](#)
Workshops:
- **Losses Relating To Ability, Aging and Dementia**
  May 10
  Adelaide, South Australia
- **Advance Care Planning education event**
  May 14
  Parkville, Victoria
- **Physical, Psychological and Spiritual Process of Death**
  May 15
  Mulgrave, Victoria

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](#) or you can join us on [CareSearch LinkedIn](#).

**June 2018 Newsletter**

The next newsletter will be circulated on Monday June 4. If you have any item you would like to have considered for inclusion, please send details by the last Wednesday in May to caresearch@flinders.edu.au.