Assembling evidence, translating knowledge

Jennifer Tieman¹, Sanderson C¹, Burns K¹,², Rawlings D¹ & Sladek R¹
¹ Flinders University
² Australian Centre for Community Services Research
Palliative care as a complex field of research and practice

- Referral based/Different underlying diseases/Specific populations
- Multi-disciplinary and different professional providers
- Diverse sites of care
- Co-morbidity, complex often specific care needs
- Research issues in developing evidence
- Emerging discipline/ recency
Issues in generating evidence

- Research infrastructure and capacity still developing
- Attitudes to research in vulnerable populations
- Technical considerations
- Defining and measuring appropriate outcomes
Issues in finding evidence

- Multiple databases
- Size of literature base
- Searching for palliative is complex
- “Missing” literature (not all work is published)
Issues in using evidence

- Characteristics of the evidence
  - Generalisability (across diseases, populations and settings of care)
  - Significance/relevance to clinical practice
- Issues for clinicians
- Characteristics of the organisation/system
- Patient aspects
What is CareSearch?

- CareSearch *palliative care knowledge network*
- Designed for those providing palliative care and those affected by the need for palliative care
- Online resource
  - Information
  - Tools and resources
- Funded by Australian Government under the National Palliative Care Program
Welcome to CareSearch. CareSearch is an online resource of palliative care information and evidence. All materials included in this website are reviewed for quality and relevance.

What's New...
on CareSearch?
in the community?
in the literature?

Quick Links
Using CareSearch
Indigenous
GPs
ComPAC
PCC4U

What is Palliative Care
For Patients
and Families
Finding Services
Clinical Practice
Finding Evidence
Education
Research Resources
Professional Groups
About CareSearch

Proudly linked to:

CareSearch
Introduction
Audio Version

Flinders
HealthInsite

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Last updated on 26 May 2009

Accessibility | Credits | Terms & Conditions | Site Map
CareSearch and Knowledge Translation

Gap between the knowledge base of palliative care and the intended users and recipients of this knowledge

CareSearch approaches:

1. Support development of the evidence base
2. Consolidate and facilitate access to literature and evidence
3. Encourage transfer and use of evidence in palliative care
1. *Support development of evidence base*

- Consolidating current research
- Grants
- Conducting research in palliative care pages
- Research Data Management System
2. Consolidate and facilitate access to literature and evidence

- Access to the published literature
  - PubMed searches
  - CareSearch Review Collection
  - What’s New
- Repository of “difficult to find” literature
  - CareSearch Grey Literature
- National Palliative Care Program repositories
  - Caring Communities Program
  - Local Palliative Care Grants Program
### PubMed Topic Searches

Follow these links to run real-time PubMed searches. They give you a broad entry point into the relevant English, palliative care related literature. When you select a topic, different search options will be provided.

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<td>Vomiting</td>
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Dyspnoea PubMed Topic Search

Select one search option for your chosen search topic.

Free full text only (likely to reduce the number of results)
Strongest evidence (systematic reviews or randomised controlled trials)
Everything

All citations
Strongest evidence (systematic reviews or randomised controlled trials)
Everything
Last 3 months only

Dyspnoea (= Dyspnea) = Difficult or laboured breathing (Source: MeSH Thesaurus)

To choose another topic, go back to PubMed Topic Searches

This page was created on 30 April 2008 and is due for review in April 2009
Immediate, real time access to relevant topic based literature
Create Your Own PubMed Topic Search

While the topics offered by CareSearch offer you quick and efficient entry into the palliative literature, you may be interested in a different topic. These instructions will help you restrict your own topic to the palliative literature. We suggest that you print these instructions to work from.

**Instructions**

**Step 1:** Run the palliative filter now

**Step 2:** CLEAR the search box

**Step 3:** Enter your topic search, select GO

**Step 4:** CLEAR the search box

**Step 5:** Select the HISTORY tag, identify the set numbers for Steps 1 and 2

**Step 6:** CLEAR the search box

**Step 7:** Combine the set numbers by typing in, eg, #1 AND #2, select GO

**Example**

Let's say you are interested in anything to do with 'narrative' in the palliative care context. A useful textbook for this concept might be 'narrative', and the correct MeSH term is 'narration'.

**Step 1:** Run the palliative filter

**Step 2:** CLEAR the search box

**Step 3:** Enter the terms narrative OR narration, select GO

**Step 4:** CLEAR the search box

**Step 5:** Select the HISTORY tag, identify the set numbers for Steps 1 and 2

**Step 6:** CLEAR the search box
CARESEARCH® palliative care knowledge network.

CareSearch Review Collection

This collection provides an easy way to find reviews on topics relevant to palliative care. It is dynamic and will change over time as new reviews are released. Our method for selecting reviews for inclusion is described in the Procedures page. This collection should not replace your own personalised search for systematic reviews on a particular topic. Users need to assess the quality of the individual reviews for their own purposes.

To submit details of a review which meets the CareSearch criteria for inclusion email caresearch@flinders.edu.au

Care Issues
- Advanced cancer
- Anxiety
- Bereavement
- Bowel
- Breathing
- Cognition
- Constipation
- Cough
- Delirium
- Depression
- Dysphagia
- Dyspnoea
- End-of-life
- Existential distress
- Fatigue
- Fluids
- Grief
- Hope
- Nausea
- Nutrition
- Oral (Mouth care)
- Pain

Specific Populations
- Assisted living
- Children
- Dementia
- Families
- Intellectual disability
- Multicultural
- Patients
- Rural and remote

Service / System Issues
- Advance Care Planning
- Advance Directives
- Communication
- Complementary Therapies
- Decision making
- Desires for hastened death
- Economics
- Education and training
- Effectiveness
- Ethics
- Models of Service Delivery
- Needs assessment
- Organ donation
- Outcome measures
- Patient carer training
- Policy
- Population issues
- Professional issues
- Quality of life
- Quality process
- Referral
- Research

Health Professionals
- Chaplains
- General Practitioners
- Nurses
- Occupational Therapists
- Social Workers
- Volunteers

Disease Groups
- Cancer
- COPD
Review Collection: Complementary Therapies


Lafferty W, Downey L, McCarty R, Standish L, Patrick D. Evaluating CAM treatment at the end...
CareSearch Grey Literature

- Database of “hard to find” literature
- Four types
  - Conference abstracts
  - Theses
  - Non-indexed journal articles
  - “grey” such as government or organisational reports
Role of the palliative care filter

• Experimentally developed content filter to retrieve palliative care literature from bibliographic databases

• Used within website
  – Harvest literature for updating and developing content pages
  – Underpins the content based PubMed searches and the create your own topic
3. Encourage transfer and use of evidence in palliative care

• Access
  – Web, free, 24/7

• Audience sensitive
  – For patients/carers
  – For health professionals

• Quality processes

• Production processes
Quality and production processes

- KNMG/NAG
- Multidisciplinary project team
- Defined search requirements
- Specified page structures for consistency
- Internal and External review
- Readability
- Usability testing
- Editing
- Currency and two year cycle
Clinical Practice Pages

- Clinical Practice pages
  - Deal with common clinical symptoms
  - Physical symptoms built around PCOC symptom set
  - Use defined searches for systematic reviews on the topic
  - Written by Australian Health professionals
Dyspnoea (shortness of breath) is described as 'an uncomfortable awareness of breathing'. It is a subjective symptom which may not correlate with measurable physical abnormalities such as hypoxia. Treating the dominant cause of breathlessness, including the contributing co-morbidities, is likely to be most effective, but is not always possible.

Shortness of breath becomes more frequent in patients as their disease progresses. It is associated with a poorer prognosis, and is usually multifactorial in patients with advanced disease.

What is known

> Evidence supports the use of either oral or parenteral opioids for relieving the symptom of dyspnoea. There is no evidence to support the use of nebulised opioids, however. [4]
> A recent meta-analysis has shown that oxygen does not improve symptoms of dyspnoea in cancer patients who are mildly or non-hypoxaemic, although there may be a sub-population who do experience benefit. [5] A systematic review found no strong evidence for the benefit of oxygen in patients with dyspnoea and advanced disease from any cause, although the numbers studied were very small. [6]
> If drainage of a malignant pleural effusion is required and is clinically appropriate, evidence supports the effectiveness of thoracoscopic talc pleurodesis. [7]
> Research from small trials supports non-pharmacological interventions including breathing re-training, activity planning and adaptation strategies, counselling and relaxation. [1] A recent Cochrane review has not identified strong evidence to support these interventions, however, most studies were not done in a palliative care setting.
Professional Groups Pages

- Recognise multidisciplinary team composition
- Developed with major bodies
Bereavement Counsellors

These pages provide access to resources and literature relevant to the practice of palliative care for Bereavement Counsellors.

Role in palliative care
This information will help you to find out more about working in palliative care. It may include narratives from those working in the area, descriptions of the role, or why the position is important.

Palliative Care Victoria has produced a brochure Grief and Bereavement Counsellors that describes how a bereavement counsellor can help. The Rural Health Education Foundation has a video program on Bereavement Care.

The Australian Centre for Grief and Bereavement has developed a resource called Minimum Standards for Bereavement Support Programs in Palliative Care Services in Victoria.

Palliative care education and training
There are different ways to develop your knowledge and skills in palliative care. Web based learning modules, short courses and specialist palliative care courses and training are offered in many organisations and universities. Further information can be found on the Education pages of CareSearch.

The Program of Experience in the Palliative Approach (PEPA) is an initiative under the National Palliative Care Program. It is a supported multidisciplinary course with work placements, offered across the country. The PEPA project is funded until 2010.

The Australian Centre for Grief and Bereavement has a range of bereavement training programs available throughout Australia.
Opioid Information

Starting an opioid
Opioid analgesics are frequently needed by palliative care patients whose pain does not respond to simple analgesics, weak opioids, and other measures – see the NPS RADAR Prescribing Practice Review on this topic.

Persistent pain should be treated promptly. A high index of suspicion about the presence of pain is needed for patients who are unable to verbalise their experiences.

Morphine, oxycodone or hydromorphone are appropriate strong opioids to start. Caution should be used when initiating analgesia with fentanyl transdermal patches (Durogesic), particularly in the frail opioid naive patient.

Some analgesics are less suitable for use in palliative care, either because of their ceiling effect, their potential for drug interactions, or other problems (see Therapeutic Guidelines - palliative care 2nd edition p102-105) These include:

- Pethidine
- Tramadol (Toremil, Tramahexol, Tramadolo, Zydoil)
- Dextropropoxyphene (Capadex, Diganol, Paradox, Deloxane)
- Buprenorphine (Nornorphine, Temgesic)
- Dextromoramide.

Switching opioids
Reasons why opioid switching may sometimes be needed include:

Quick Links
- Online Prescribing Medicine
- Translating and Integrating Authority Prescriptions
- State Based References
- NPS RADAR Prescribing Practice Review
- Pethidine
- Tramadol (Toremil, Tramahexol, Tramadolo, Zydoil)
- Dextropropoxyphene (Capadex, Diganol, Paradox, Deloxane)
- Buprenorphine (Nornorphine, Temgesic)
- Dextromoramide.
Finding Evidence Pages

- Recognises that evidence – use cycle involves many steps and components
- Describes elements
- Links to resources and facilities
- Palliative care context
Finding Evidence

These pages are designed specifically for health professionals. They look at the role, nature and sources of evidence and the application of evidence in practice.

While patients and families may find helpful information here, more tailored links are available, such as Topic Information and Finding Out More in the Patients and Families pages.
Other Key Features

• Find and access information
  – web-based, 24/7

• Recognises locality differences
  – state-based, rural and remote pages

• Diverse problems and solutions
  – Multiple entry points
  – Shared resources for whole community
Patients, carers and consumers as participants and recipients

- Knowledge translation process
  - NHMRC Consumer
- Role in clinical trials
- Increasing use of online resources by consumers
- CareSearch resources for patients, carers, general community
CareSearch would like to thank the many people who contribute their time and expertise to the project including members of the National Advisory Group and the Knowledge Network Management Group.

CareSearch is funded by the Australian Government Department of Health and Ageing as part of the National Palliative Care Program.

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