Finding and generating evidence in palliative care: CareSearch’s role

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Knowledge needs in palliative care

• Population health considerations
• Symptom and care issues
• Service models and care settings
• Professional/Methods of working
• Family as unit of care
• Care gaps, needed evidence
• Technical and process skills
• Progressing palliative care
Is there an evidence base?
Growth in palliative care literature

- 1981-1985
- 1991-1995
- 2001-2005

- Pall Care Citations
- Pall Care Clinical Trials
Material not on Medline
Increase in journals and citations

![Graph showing increase in journals and citations from 1995 to 2005. The graph indicates a steady increase in the number of journals and citations over time.](https://www.caresearch.com.au)
Increase in journal with regular content

No of journals with 10 more citations per year

1995 | 2000 | 2005
---|---|---
40 | 60 | 120

CARESEARCH
palliative care knowledge network
www.caresearch.com.au
Conversion rates: conference to journal

![Graph showing conversion rates from conference to journal between 1988 and 1999. The graph compares unpublished abstracts and published abstracts over the years. The y-axis represents the number of abstracts, ranging from 0 to 120, and the x-axis represents the years from 1988 to 1999. The graph indicates fluctuations in conversion rates with a trend towards an increase in published abstracts.]
Palliative care: Evidence considerations

- Nature of evidence base needed
  - Complex, referral based, comorbidity, multidisciplinary

- Best available evidence
  - Strength of the evidence
  - Generalisability, applicability

- Expanding, not comprehensive
  - Identifying gaps
Palliative care: Evidence retrieval

• Growing, evolving, evidence base
• Multiple disciplines doing research
• Complex search basis
  – Many constructs
• Not all in one place
Palliative care: Evidence generation

- Sample size concerns
  - Multisite studies
- Clinical researchers, skill development
- Project/trial management infrastructure
- Priority topics for research
- Research funding needs
Palliative care: Evidence use

• Use by:
  – Health professionals, Services and organisations, Consumers, Discipline or profession, System

• Barriers
  – Awareness
  – Efficiency, relevance, quality
  – Interest in, commitment to
What is CareSearch’s role in the palliative care evidence cycle?

• Generating,
• Finding,
• Encouraging use
What is CareSearch?

• Funded by the Australian Government as part of National Palliative Care Program

...provide a one stop shop of information and practical resources that serves the needs of all providing palliative care or affected by palliative care...supporting the development of evidence, disseminating information that will support the translation of this evidence into practice and prevent duplication of effort around Australia.
More than just a website

- Research Data Management System
- Evaluated resources and links
- Databases and information repositories
- Finding evidence: Brokered resources & How to guides
- Content pages: Topics for specific users
- News and updates
- Virtual team resources
- Education Options: Links and online
CareSearch: Generating evidence

- CareSearch research
- Research Resources
  - Conducting research pages
  - Finding grants
- RDMS
  - Online data management
- Professional Connect
CareSearch Research Areas

• Filter development
  – Palliative Care Filter
  – Heart Failure Filter

• Knowledge translation in online environment
  – eHealth literacy
  – Barriers to web use
Filter development: From this…

Run the palliative care filter now
To this......
Research Data Management System

- Online survey system allowing data entry from multiple sites anywhere in the world
- Web and print version compatible
- Variable rights and security roles
- In built data analysis tool with filters, graph, percentages, tables, etc
- Capacity to export data to programs such as Excel, SPSS
- Audit trails and email alerts
Contributes to evidence generation: Current examples
1. Multisite clinical trials (e.g. PaCCSC)
2. Service and organisation audits and surveys (e.g. PCQ consumer survey)
3. National Standards Assessment Program self assessment
Professional Connect

• Forums for communication and exchange
  – Private, registered, open
  – Registered pages for project/research shared resources
  – Shared project tools
    • Calendar, polls, alerts

• Examples of current user groups
  – PaCCSC
  – Victorian Nurse Practitioner Project
CareSearch: Finding evidence

- Evidence Summaries
- PubMed Topic Searches
- Repository of hard-to-find evidence
- CareSearch Review Collection
Clinical Practice: Evidence Summaries

• Clinical Practice pages
  – Based on review of systematic reviews
  – 17 clinical pages
  – Related PubMed Topic Search
  – Quality and currency processes

• Specific Populations pages
Delirium is a condition of disturbed consciousness, with reduced ability to focus, sustain or shift attention. The DSM 5 diagnostic criteria for delirium require:

1. altered cognition or a perceptual disturbance (which is not due to dementia),
2. symptoms develop over hours to days and tend to fluctuate during the course of the day, and
3. evidence of an organic cause for the delirium.

Delirium may be:

- hyperactive (presenting with agitation, hyperactivity, and restless movements), or
- hypoactive (presenting with drowsiness, lethargy, and reduced levels of arousal), or
- a mixed pattern in which the symptoms fluctuate between hyperactive and hypoactive [2].

Delirium is often reversible, although there is evidence that in some patients it may be associated with longer term cognitive problems [3].

Delirium is extremely common in palliative care patients [4], and becomes more frequent towards the end of life, and is associated with a worsening prognosis [3]. The diagnosis is often missed, or may be confused with delirium or dementia. Impressive delirium in particular is under-diagnosed [4]. Nonetheless, the importance of making the diagnosis is that delirium is a potentially treatable problem, and one which causes serious distress to patients and their families.

Much of the evidence about prognosis and treatment of delirium comes from the aged care and critical care literatures. However, the focus of care in these populations is different from that in palliative care, particularly in very advanced disease [7]. In palliative care patients, delirium is frequent and multifactorial. The underlying process, though reversible in many instances, may be irreversible in advanced disease, or due to other factors the decision may be made not to pursue active intervention or intervention.
Finding Evidence section

• How-to guide on finding evidence
  – Sources and databases
  – How to create searches
  – Downloadable guide

• Evidence resources
  – PubMed Topic Searches
  – CareSearch Review Collection
  – CareSearch Grey Literature
PubMed Topic Searches

• Hyperlinks to topic based searches run in PubMed based on Palliative care filter
  – 60 topic searches
  – Immediate, real time
  – 5 options based on
    • Strength of evidence
    • Free full text only
    • Most recent
CareSearch Databases

• CareSearch Grey Literature
  – Conference Abstracts
  – Non-indexed Articles
  – Theses
  – Research Studies Register
  – National Palliative Care Program
  – Other Grey

• CareSearch Review Collection
CareSearch: Encouraging evidence use

• Audience specific content formats
• Continuing Professional Development
• Partnerships and integration
• Alerts and reminders
Audience Specific Content

• Audience specific content pages
  – Clinical Practice = evidence syntheses
  – Nurses hub/GP hub = practice interpreted
  – Patients/carers = consumer oriented

• Extensions to further resources
  – Quality appraised
Partnerships with Projects/Organisations

• Quality Improvement
  – NSAP/PCOC
• ANZSPM
  – Clinical Indicators
• AGPN
  – Rural Palliative Care Program
• PCNA
  – Nurses Hub
News and Updates

• What’s new on CareSearch
• What’s new in the community
• What’s new in literature
• @CARESEARCH
• Alerts
Summary: Evidence and CareSearch

- Identifies systematically palliative care evidence
- Facilitates access to this evidence
- Uses evidence in designing and developing resources
- Contributes to the evidence base by researching specific project areas
- Supports those generating and using evidence by providing tools, resources, information
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