

A very practical approach to translating the evidence

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Ophthalmology Workshop, Nov 2013

CareSearch is funded by the Australian Government Department of Health and Ageing.



Outline

- Evidence and Practice
- CareSearch/Palliative Care
- More than webpages: What Lies Beneath
- Exemplar Resources
 - Clinical Evidence
 - CareSearch Hubs
 - Search Filters
 - Research Data Management System
- Use and Evaluation



Evidence and Practice



Expectations of clinicians

- Changing health environment
- Population health
- Best practice/ EBM/Research evidence
- Multidisciplinary approaches
- Care coordination/continuity of care
- Currency of practice



Issues

- Finding the evidence
- Managing the evidence
- Building the evidence
- Applying the evidence





CareSearch/Palliative Care



About Palliative Care

- Cure is not the goal of care
- Referral based, multidisciplinary, comorbidity
- Care provided in many settings
 - Many health professionals
 - Family carer
- Patient and family as unit of care
- Expanding, diffuse knowledge base



Nature of the evidence base

- Multiple databases
 - Unique contribution from Medline, CINAHL, PsycINFO and Embase
- Size of literature base/Number of journals
 - 56,000 palliative articles in Ovid Medline alone
 - In 2005 6,983 citations in 1,985 journals (or 19 per day).
- Searching for palliative is complex
 - Indexing is not precise (9 MeSH terms and 3 textwords retrieved only 45.4% of the palliative care literature)
 - Not only in specialist journals (4% of general biomedical journal articles relevant to palliative care)
- "Missing" literature
 - Conference conversion rate low Approximately 16% compared to average of 45%





Palliative Care Context

- Population health considerations
 - Ageing population
 - Specific needs groups
 - Malignant, non-malignant
- Policy Drivers
 - Health reform agenda
 - National Palliative Care Strategies (1 & 2)
 - National Palliative Care Program (2000-2010)
 - Senate report into palliative care in Australia
 - Living Longer, Living Better
- Models of care delivery



Background to CareSearch

- Funded by Department of Health and Ageing since 2006
- Purpose
 - provide a one stop shop of information and practical resources that serves the needs of all providing palliative care or affected by palliative caresupporting the development of evidence, disseminating information that will support the translation of this evidence into practice and prevent duplication of effort around Australia.
- Governance
 - Managed by Flinders University (Palliative and Supportive Services)
 - Knowledge Network Management Group
 - National Advisory Group
- Framing factors
 - For those providing palliative care (eg specialist services, GPs) and for those affected by palliative care (eg patients, carers,)
 - Relationship to the evidence and use of knowledge
 - Online







More than webpages: What lies beneath



Knowledge Translation

- Knowledge to Action (KTA)¹: Project framework
 - Systematic approach to evidence identification/assembly
 - Contextualisation
 - Barrier analysis
 - Evaluation
- Research processes

1. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, Robinson N. Lost in knowledge translation: time for a map? J Contin Educ Health Prof. 2006 Winter;26(1):13-24.



	Knowledge Creation			Action Cycle							
	Knowledge Inquiry	Knowledge Synthesis	Knowledge Tools	Problem Available	Adapt Knowledge	Assess Barriers	Intervention	Monitor Use	Evaluate Outcomes	Sustain	
Project Activity: Macro	Evidence Overview	Review of Strategies (Haynes 6S)	Quality Manual	Scoping Study	Review of Web Design & Process	Review Aust Web Access/Use	CareSearch Website and Functions	Web Metrics	Evaluation Framework	Palliative Care Partnerships	
Project Activity: Projects	RDMS - Research	Review Collection	PubMed Search Topics	PCOC NSAP	Audience identification	Consultation Workshop	User Testing	Livestats	Online surveys	Presentation Publication	
	Grey Literature Database	Page Structure	Patient Information Picker	Consultation Tour	Page and Content Formats	Consultation Tour	NAG Working Groups	Google Analytics	Page view analyses	Community Engagement	
	Automated Retrieval			Consultation Workshop	Web Design	Subgroup Feedback			Stakeholder Interviews	Project Partnerships	
	PC filters AutoAlerts			NAG KNMG	Navigation				User Feedback		
				•	•	•	•				
Project Activity: Research	Bibliometric Analyses		Palliative Care Filter			eHealth Literacy Digital Divide	Translational Tools	Web Metric Analysis	ICT Evaluation		
			Heart Failure			Online	Carer Toolkit				
			Filter			Learning					
						Learning Evidence					



Developing functionalities

- Develop functions and resources:
 - User needs
 - Evidence for formats, processes
- Facilitate knowledge translation
 - Relationship to the evidence
 - Relationship to the context



Exemplar Resources: Clinical Evidence



Clinical Evidence

- Topics with user community:
 - Symptoms, ACP, Diseases
- Syntheses of systematic or structured literature reviews
- Page structure
 - Key Messages
 - Implications for practice
 - Areas of contention
 - Facilitated access to the underlying evidence base: References, PubMed Searches

Main Menu

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Obstruction

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Specific Diseases

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> Fatique

> Nausea

> Pain

Respiratory Secretions

> Complementary Therapies

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Search

e care knowledge network

PubMed Searches

Strongest evidence

Strongest evidence

About these searches

Review Collection

Dysphoea

Dyspnoea Free full text only

All citations

Everything

Everything Last 3 months

You are here: Clinical Evidence » Patient Management » Breathing » Dyspnoea

Dyspnoea

Dyspnoea (shortness of breath) is described as 'an uncomfortable awareness of breathing'. [1] 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, [2] is associated with a poorer prognosis, [3] 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. [5-6] 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. [7]

The use of nebulised frusemide for dyspnoea has been investigated. A recent systematic review suggests it is a promising approach, although the included studies were small and diverse. [8]

If drainage of a malignant pleural effusion is required and is clinically appropriate, evidence supports the effectiveness of thoracoscopic talc pleurodesis. [9]

Research from small trials supports non-pharmacological interventions including general support, breathing re-training, activity planning and adaptation strategies, counselling and relaxation. [1, 10] These are complex interventions and it is not clear which components in the package may be most effective. A recent Cochrane review has not identified strong evidence to support these interventions, however, most studies were not done in a pallative care population and were small. [11] Nurse or physiotherapist-led interventions including breathlessness clinics may improve management of dyspnoea in palliative care patients with lung cancer. [12] For Chronic Obstructive Pulmonary Disease (COPD) patients who are able to participate in pulmonary rehabilitation, there is evidence of a clinically significant benefit in terms of dyspnoea, fatigue and wellbeing. [13]

Benzodiazepines are frequently prescribed for management of distress associated with dyspnoea, but have not been well studied. They were not of benefit in four out of five randomized controlled trials when used in COPD, [14] but numbers were small.

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Exemplar Resources: Search Filters



Why a search filter?

- "Evidence based" search = known effectiveness
- Benefits
 - Saves time



- Increases likelihood of quality retrievals
- Removes individual search burden
- Embeds technical expertise
- Facilitates knowledge translation



Developing search filters

- Not an expert search, research based
- Informed by Expert Advisory Group
 - Functional utility
- Filter Development Process
 - Gold standard, Term identification, Strategy testing, Post hoc relevance
- PubMed applications
 - Harnessing the ease of the web, Open access, free to use, allows hyperlinking





PubMed: Palliative care filter

advance care planning[mh] OR attitude to death[mh] OR bereavement[mh] OR terminal care[mh] OR hospices[mh] OR life support care[mh] OR palliative care[mh] OR terminally ill[mh] OR death[mh:noexp] OR palliat*[tw] OR hospice*[tw] OR terminal care[tw] OR 1049-9091[is] OR 1472-684X[is] OR 1357-6321[is] OR 1536-0539[is] OR 0825-8597[is] OR 1557-7740[is] OR 1552-4264[is] OR 1478-9523[is] OR 1477-030X[is] OR 0749-1565[is] OR 0742-969X[is] OR 1544-6794[is] OR 0941-4355[is] OR 1873-6513[is] OR 0145-7624[is] OR 1091-7683[is] OR 0030-2228[is] OR ((advance care plan*[tw] OR attitude to death[tw] OR bereavement[tw] OR terminal care[tw] OR life supportive care[tw] OR terminally ill[tw] OR palliat*[tw] OR hospice*[tw] OR 1049-9091[is] OR 1472-684X[is] OR 1357-6321[is] OR 1536-0539[is] OR 0825-8597[is] OR 1557-7740[is] OR 1552-4264[is] OR 1478-9523[is] OR 1477-030X[is] OR 0749-1565[is] OR 0742-969X[is] OR 1544-6794[is] OR 0941-4355[is] OR 1873-6513[is] OR 0145-7624[is] OR 0749-1565[is] OR 0742-969X[is] OR 1544-6794[is] OR 0941-4355[is] OR 1873-6513[is] OR 0145-7624[is] OR 0749-1565[is] OR 0742-969X[is] OR 1544-6794[is] OR 0941-4355[is] OR 1873-6513[is] OR 0145-7624[is] OR 1091-7683[is] OR 0030-2228[is]) NOT Medline[sb]) AND English[la]





Search Filters

- Current Filters
 - Palliative care
 - Heart failure
 - Lung cancer, NSCLC and SCLC
 - Primary health care
 - Residential aged care facilities
 - Dementia
 - Aboriginal and Torres Strait Islander health
- In Development
 - Bereavement
 - Sarcoma
 - Glaucoma



Exemplar Resources: Research Data Management System



Building the Evidence Base

Need to support palliative care research, particularly high quality evidence:

- Lack of research infrastructure
- Need for participation from multiple sites
- Experience and capacity
- Technical support



Part of Research Resources

- Conducting research in palliative care
- Grant and funding sources
- Research Studies Register
- Research Data Management System (RDMS)
- Professional Connect



About the RDMS

- System functions
 - Enables the online design of data collection forms and questionnaires; various styles, question formats
 - Allows for web-based and email-based form completion
 - Enables data entry from multiple sites with a single coordinating site
 - Provides for basic reporting of results with features such as percentages, graphs, and tables
 - Allows export of data to other programs such as Excel, Access or SPSS.
- Availability
 - Designed to support the palliative care community
 - Access requires formal agreement

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Exemplar Resources: CareSearch Hubs



Why a Hub?

- Organises evidence for use
- Consolidates relevant materials for a particular group
- Reduces burden for the individual clinician associated with identifying, retrieving, sorting and appraising
- Provides home/entry point
- Recognises engagement of particular group in palliative care/EOL



ARCH® tive care knowledge network Main Menu Professional Login | Feedback | Email Page: 🖂 | Fontsize: 🗛 🗛 | Search Groups What is Palliative Care? You are here: Professional Groups » GP Hub Home RAC Hub For Patients and Families Nurses Hub Home **GP Hub Home** Finding Services GP Hub Home Clinical Evidence Finding and Using Evidence > Patients Needing Palliative Patients Needing Palliative Managing Symptoms Care **Opioids and Pain** Care Education Discussing Palliative Care Important Skills > Managing Symptoms Monitoring Prognosis Support for Carers Research Resources Advance Care Planning Managing Emergencies > Making it Work in Your Professional Groups When to Refer If Patients and Families Aren't Practice Coping About CareSearch Specific Populations Complex Problems > The Dying Patient Contact CareSearch PubMed Searches: General Practitioners > Following Up the Bereaved Making It Work In Your The Dying Patient Home General Practice Helping You Support Families **Practice** Review Collection Medicare Information State by State Requirements General Practitioners > Professional Development Prescribing Issues Home Visits > GP Resources In Residential Aged Care What's New! For Rural GPs Cancer Council GP Portal Allied Health Sneak Peek Continuity of Care Following up the Bereaved Professional Development Aboriginal Health Workers When to Refer (Bereaved) Self Care Shortcuts to the literature for Bereavement Counsellors GPs Dietitians Resources GP Resources (All by topic) Doctors Printable Patient and Carer Resources Music Therapists This page was last updated 24 January 2013* Occupational Therapists Back to top Print Page: Paramedics Pastoral Care Workers



CareSearch Hubs

- GP Hub
- Nurses Hub
- Residential Aged Care Hub
- Allied Health Hub
- Patients, Carers, Families





Evaluation and Use



Usage

- > 60,000 visits per month
- > Over 400,000 page views per month
- > Registered for newsletters > 4,500
- > Engagement of the clinical community
- > Project integration with other national activities in palliative care (e.g. PaCCSC, NSAP)
- > Relationships with research/project teams around online applications of findings and research work
- > 21 evaluation projects completed (formative, summative and process)



Assessing Value: RDMS

- National and international users
 - 20 organisational agreements, 200 surveys and 500 registered users
 - Enables data collection for national standards assessment
- RDMS used for PaCCSC

– First of RCT results published (Ketamine for pain)

• 2010 Evaluation Survey (Users and Stakeholders)



Assessing value: PubMed searches

- Usage
 - Each PCF PubMed search is used between 3 and 20 times per day
- PCF Effectiveness Study
 - Clinician searches are basic
 - PCF outperforms clinicians searches
 - PubMed searches identified literature the health professionals hadn't found



Possibilities for Ophthalmology



Considerations

- Structuring your knowledge base
 - Who are your knowledge users
 - What already exists
 - Role of evidence in practice
- What would add value?
 - Best practice summaries
 - Education and training resources
 - RDMS
 - Search solutions
 - Information for patient and families
- How will users learn about it?



CareSearch in conclusion

- Not just a website, an online knowledge resource
- Activity is driven by knowledge translation framework
- Evidence is the central construct
- Research sits alongside the project



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.

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