CareSearch: A literature and research database for palliative care

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Background

Evidence based practice (EBP) in palliative care continues to be a challenge. Palliative care is informed by work from many fields of study and access to the best available evidence can be difficult. As an emerging field, the evidence and research that has been carried out has not always been captured in the literature that is indexed by the common electronic bibliographic databases such as Medline, CINAHL, Embase, or PsycINFO.

There are many sources of potential loss that prevent researchers and clinicians having the most comprehensive evidence base possible for palliative care. Reasons include:

• Researchers not always making their work available through presentation at conferences or by publication
• Relevant studies existing only in the grey literature such as conference proceedings or reports
• Published articles not being indexed on the common bibliographic databases either because specialist journals in palliative care have not been indexed or are variably indexed
• Inability to locate suitable material through searching and lack of palliative hedges and filters to assist in searching
• Work published outside the biomedical journals and not tracked through the commonly used bibliographic databases.

This lack of access to relevant research, review or opinion makes the evidence base for the practice of palliative care much less comprehensive than it could be.

The Evidence Based (Palliative Care) Project funded under the National Palliative Care Strategy had three specific aims:

1. To capture and collate Australia’s “missing” palliative care evidence and the missing published literature in palliative care
2. To make this evidence accessible to inform best practice
3. To promote EBP in palliative care through an electronic cyber community.

Methods

A National Reference Group comprising clinicians and researchers with skills in EBP, palliative care, general clinical care, information systems and research evaluation was established. In conjunction with the CareSearch Project Team, the National Reference Group identified literature sources and developed a schema for review and evaluation.

Four areas of missing literature were identified:

• Conference abstracts: Abstracts presented at Australian conferences from 1980 that deal with issues in palliative care
• Non-indexed journal articles: Articles published in journals but not indexed or variably indexed on the common electronic bibliographic databases
• Theses and Treatises: Masters and PhD theses from Australian universities that deal with issues in palliative care
• Grey literature: Government documents and policy, and research and service reports from agencies involved with palliative care.

Relevant organisations for each of the above groups were approached regarding access to relevant material for inclusion on a publicly available resource. Material that was supplied was then reviewed by members of the Project Team or National Reference Group for relevance. For conference abstracts an additional evaluation using a specifically designed proforma was undertaken to provide guidance as to the level of evidence associated with the work being presented at the conference.

The Project Team worked with Morton Blacketer, a website developer, to build a structured database to house the results of the literature collection and a search engine to interrogate the database.

Results: CareSearch Website

CareSearch is being developed as an electronic resource for palliative care researchers and clinical practitioners providing care for people with a life limiting illness.

Results: Project Analysis

Data Collection

Data collection began in 2002 and is ongoing. As at March 2005, there are over 2 600 items in the literature databases.

• Conference Abstracts (n= 1 989) To create the conference abstracts database, 25 conference organisers were approached in the initial phase in 2002. All organisations supplied books. One hundred and eleven books were reviewed and 1 690 abstracts were assessed as being relevant to palliative care. Over 20% of these abstracts have been evaluated for evidence level to date. Additional conferences and conferences held since the initial collection are also being added to the database.
• Non-indexed journal articles (n= 410) Twelve palliative journals were reviewed from initial publication to June 2002. A total of 8 398 items were identified with 90% of these being indexed in one of the four main electronic databases (Ovid Medline, CINAHL, Embase or PsycINFO). Of the remaining 831 items, 431 were deemed not to be articles (eg book reviews, video reviews, conference summaries). The other 410 items were regarded as research or commentary and had had citations included on CareSearch with the permission of the publishers.
• Grey Literature (n= 100) State and federal government departments with responsibilities for palliative care and national and state organizations associated with palliative care were approached to identify and provide items for inclusion in this database. To date 100 reports, policy documents or reviews have been included on the literature databases.
• Theses and Treatises (n= 78) Australian Universities were asked to identify potential theses relating to palliative care in its broadest concept. Identified theses were then reviewed by members of the Project Team for relevance. Citations and abstracts of seventy-eight theses directly relevant to palliative care have been included. Much of this work has not been published.

* Number of items as at March 2005

Conference Conversion Rates

The rate of publication within peer-reviewed journals of presentations at conferences can be used as a measure of the effectiveness of the dissemination of knowledge within a field or discipline. The average rate of conversion for a biomedical meeting is around 45%.

Preliminary analysis of the initial set of conference abstracts identified for inclusion in the literature database for CareSearch show that the conversion rate for these abstracts is only 16%. This finding indicates that much of the work in palliative care within Australia has not been accessible and highlights the value of literature repositories such as CareSearch.

Conclusions

CareSearch has systematically demonstrated that there is an Australian evidence base contributing to palliative practice and highlights this output in a public forum.

Over 2 600 palliative items had been included in the database. The volume of data and materials identified supports the initial perception that there was a large “missing” literature not previously available.

Inadequate access to this “missing” literature created a knowledge deficit and left the research community at risk of repeating completed work rather than building on existing knowledge.

CareSearch complements rather than duplicates existing resources and ensures the most comprehensive coverage of Australia’s palliative care material.

This approach to comprehensive coverage of the Australian palliative care information also facilitates identification of gaps in knowledge.

The website’s structure and features support EBP and the development of critical skills for identification and appraisal of information.

Acknowledgements:

This project could not have been completed without the generous contribution of time and expertise by members of the National Reference Group.

The Australian Government Department of Health and Ageing provided the funding for this project. Morton Blacketer developed the website, graphic design by CDAA.

For further information: