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Article

Discovering the dementia evidence base: Tools to support knowledge to action in dementia care (innovative practice)

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Abstract

Dementia requires expert care and decision making, based on sound evidence. Reliable evidence is difficult for busy dementia care professionals to find quickly. This study developed an experimentally tested search filter as an innovative tool to retrieve literature on dementia. It has a known retrieval performance and can be provided as an open access web link directly to current literature. The Dementia Search Filter was developed using validated methodology. An Expert Advisory Group of dementia care practitioners and researchers ratified a representative set of relevant studies and undertook post hoc relevance assessment, to ensure the usefulness of the search filter. The Dementia Search Filter is published on two websites and combined with expert searches to link to evidence on dementia, at end of life in aged care settings and more generally. Evidence accessed by the Dementia Search Filter will help overcome barriers to finding current relevant research in the field, for practitioners, researchers and decision makers.

Keywords

Search filters, information retrieval, dissemination, diffusion, evidence-based practice

Introduction

The widespread condition of dementia, touching many lives, requires expert care and decision making based on sound evidence. Evidence-based practice (EBP) is well-established in health care, aiming to ensure better outcomes by incorporating what is shown to be effective from research in clinical practice and service delivery. While there are issues about the interpretation and application of EBP, there appears to be general agreement about the importance of identifying and assessing the evidence for its meaning for care provision (Greenhalgh, 2014; Irving, 2013; LeCouteur, 2013; Tilly, 2004).

Allied to the evidence-based medicine model is the concept of knowledge translation, that is, the application of evidence to practice. A growing body of literature and investigation considers knowledge translation in general (Elwyn, 2007; Tabak, 2012; Tetroe, 2011), and its contribution to dementia practice (Irving, 2013; Morley, 2014; Rahman, 2012; Rolland, 2013). Studies have shown a lack of knowledge amongst residential aged care nursing staff in the areas of sleep disorders, nutrition and antipsychotic medications, relating to patients with dementia (Brown, 2014; Beattie, 2014; LeMay, 2013).

Common to both knowledge translation and EBP is the essential step of finding and identifying evidence. No model for translating evidence into practice can omit the need to find the evidence first. There are significant challenges to finding this evidence, usually within journal articles in bibliographic databases. Care professionals must know where to look and how to look and have access to each bibliographic database.

With rapidly increasing numbers of articles, finding relevant current evidence can be difficult. PubMed currently contains over 24 million abstracts (PubMed, 2014). Searching effectively in online bibliographic databases requires knowledge of varied terminology in a given field and the particular grammar of searching each database. Dementia care professionals may not have expertise in information retrieval, nor the time, confidence or willingness to frame complex search strategies to find the best available evidence. Yet important health care decisions will be made based on their search results.

This study's purpose was to develop a searching resource for dementia care professionals to shortcut access to the literature and evidence base and which could be made available through the Web.

Methods

The Australian palliative care knowledge network (CareSearch) (<http://www.caresearch.com.au>) in partnership with HammondCare (<http://www.hammond.com.au>) has produced a set of evidence-based services to connect dementia care professionals to evidence about best practice in dementia care. Within this project a Dementia Search Filter was developed.

A search filter is a validated search strategy designed to retrieve information relevant to a particular topic or study design from an online bibliographic database. The methodology used to develop the filters is validated and transparent; the filters have a known retrieval effectiveness that is validated and published. Information about previously published search filters developed by CareSearch can be found on the web site.

This study was conducted between October 2012 and May 2013. We provide here a brief summary of the methodology employed to develop the Dementia Search Filter. More details are available on request from the authors.

The methodology contained the following phases: (1) assessment of options for and construction of a gold standard set; (2) identification and testing of terms; (3) construction and validation of the search filter. The gold standard set is a set of articles that have been identified and endorsed by dementia care professionals and known to be relevant to professional practice. Search terms are tested (individually and together) for their effectiveness in finding articles in this set. This work was undertaken in OvidSP Medline, which has particular functionalities enabling more controlled storage and testing of bibliometric data. The translation phase then validated the OvidSP Medline-derived search filter for the PubMed environment. Finally, the search filter was deployed for use through the web. Figure 1 outlines the steps.

[Figure 1]

Figure 1: Diagram of phases of work

The project was informed by an Expert Advisory Group (EAG) of representative clinicians, policymakers and researchers, providing advice throughout on scope of the search filter, choice and composition of the gold standard reference set; relevant terms to be tested for inclusion in the filter; and specific searches to be published using the search filter. This group ensured that the searching resource was relevant to those working in dementia and practical for intended users.

Gold Standard Set

The gold standard set is used to test retrieval performance, ensuring that the search filter is of optimal sensitivity in retrieving relevant literature. It is a set of references representative of the full scope of the field of dementia. The gold standard set was created from included studies of a set of systematic reviews, ratified as representative of dementia by the EAG. This set was divided randomly into three subsets: term identification set, filter development set and filter validation set. This ensures that development and testing can be done in different sets, thus minimising bias.

OvidSP filter development

Candidate search terms for testing were acquired by frequency analysis of titles and abstracts of TIS references, as well as identified relevant MeSH terms (that is, authorised medical subject headings used in the Medline and PubMed databases) and other textwords confirmed or suggested by the EAG. Terms were tested singly and in combination, resulting in a draft strategy (best performing combination of terms) for the OvidSP Medline search filter. We tested its sensitivity in the FVS (number of references retrieved as percentage of number of relevant items in the set). Members of the EAG undertook post hoc relevance assessment of the performance of the OvidSP Search Filter (dual reviewers).

PubMed Filter

While an Ovid Medline search filter is helpful for busy clinicians and academics, it requires registered and paid access. Using PubMed opens the search for articles to all with Web access. PubMed contains an indexed subset, effectively equivalent to Medline; it also contains a non-indexed subset of records not yet added to Medline or that will never be in Medline. To capture relevant references in both sets, and provide a tool of greater clinical usefulness, we used validated experimental methodology for translation of the OvidSP Medline version of the filter to an effective PubMed version (Damarell, Tieman, & Sladek, 2013).

Web Deployment

The translated Dementia Search filter for PubMed can be embedded on a web page as a URL link to real-time PubMed search results. On the search filter base we created expert topic searches within the Clinical Evidence pages on the CareSearch website, for topics within the broad scope of dementia viewed as clinically important by the EAG. Figure 2 shows a section of the Clinical Evidence page on the CareSearch website containing the dementia PubMed searches.

[Figure 2]

Figure 2: Dementia PubMed searches on the CareSearch website, using the Dementia Search Filter.

Results

The initial filter (OvidSPv1) was developed within OvidSP Medline. This three term strategy retrieved 97.17% of references in the FVS. The best performing single term was the MeSH term **exp Dementia/** with a recall of 92.45% in the FVS. Note that this term is exploded to retrieve all the narrower terms beneath it in the MeSH hierarchy. The EAG confirmed each narrower term relevant. The addition of the truncated textwords **dement\$.ti,ab** and

alzheimer\$.mp improved retrieval of relevant records, resulting in a recall of 97.17% in the FVS. Three reviewers undertook post hoc relevance testing. Items receiving 2 or more Yes ratings (194/250 = 77.6%) were considered relevant. Post hoc relevance testing was also undertaken of the retrieval performance of the non-indexed PubMed component.

[Table 1]

The Dementia Search Filter has been utilised within the Clinical Evidence>Specific Diseases section of the CareSearch website (<http://www.caresearch.com.au/caresearch/tabid/2785/Default.aspx>), and on the Flinders Filters Website (<http://www.flinders.edu.au/clinical-change/research/flinders-filters/search-filters/dementia/dementia-search-filter.cfm>). The Dementia section of CareSearch provides pages written by expert clinicians on the topic of dementia within palliative care, in a residential aged care setting. Links to PubMed searches are embedded within pages, providing real-time access to the latest PubMed search results. A full page of PubMed Dementia Topic Searches contains over 24 searches on clinically useful topics. For each topic, there is the option to see only those items available in free full text immediately.

On the Flinders Filters website, the pure Dementia Search Filter has been deployed to offer access to PubMed literature on all aspects of dementia. Topic searches of interest to dementia clinicians and researchers across the broad spectrum of dementia care and research have been made available. The choice of these 35 topics was confirmed by general dementia specialist members of the EAG.

Discussion

We have successfully created a validated Dementia Search Filter for OvidSP Medline and PubMed and utilised it on two websites to help connect clinicians and researchers with the best available evidence for dementia. Our analysis of terminology, literature base and performance of search terms, including relevant MeSH headings, showed that this subject area is well-delineated and well-indexed in Medline. The intuitive search term **exp dementia/** (and its PubMed equivalent **dementia[mh]**) will retrieve 91.98% of records in the gold

standard set ratified by our EAG. However, the addition of two truncated textwords improves recall by 4.7%, a number which may be significant for clinical settings and for research requirements (e.g. searches for systematic reviews).

One key technical challenge in the PubMed translation was accounting for all subordinate terms below the term **Dementia** in the MeSH hierarchy, (essentially the names of the different types of dementia). For each subordinate term, we tested the textword equivalent for improved recall. By testing, and embedding the best performing terms in the search strategy, we provide an effective search for clinicians and others to use without needing to commit time and effort to typing in each kind of dementia.

It became clear through our discussions with expert advisors that their work contexts and differing clinical and research information needs would govern our deployment of the filter in different contexts. This point about different information needs and ways of accessing information has also been made within the literature. Irving et al. (2013) write: "The different stakeholders for dementia research have different capabilities and needs when it comes to accessing and evaluating evidence." Similar points are made by Cook and Rockwood (2013) and by Rahman et al. (2012). The collaboration with HammondCare focussed on resources to support dementia care in residential aged care and a palliative care context. For this purpose we utilised the Dementia Search Filter within the Clinical Evidence pages on the CareSearch website where we combined it with the Palliative Care Search Filter and the Residential Aged Care Search Filter to target that particular evidence. Because in the course of this project we had developed a highly sensitive Dementia Search Filter, we chose to publish it on the Flinders Filters site where we could make it available for anyone working in any aspect of dementia care or research, extending its usefulness to the general dementia community.

Translating the Dementia Search Filter for use in PubMed allows us to embed it in easy-to-use links on a web page, as a free resource without a logon, taking users seamlessly to real-time search results. It also enables the segmentation of results so that

users can choose to see only those that are immediately available free in full text. For those such as nurses working in residential aged care, without access to costly commercial databases, this provides a valuable quick connection to evidence.

We believe that the need for evidence-informed practice has been identified as significant within dementia care and that the first step toward achieving this is to discover that evidence. The Dementia Search Filter is a new validated tool to provide trustworthy and effective searching for current evidence about dementia. We have embedded it with sets of topic searches on two different websites, designed to fit different working contexts and information needs. We aim to assist those working in this increasingly important and demanding field to find the best research to support their practice and contribute to better health outcomes for all.

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Conflict of interest

There is no conflict of interest to be declared in relation to the authors or organisations associated with this study.

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TABLE 1
Performance of search filter versions

Search Version	Search Strategy	Retrieval performance	Relevance assessment
Search Development in Indexed Set (Medline)		Filter Validation Set	Open Medline
OvidSP	exp dementia/ or dement\$.ti,ab. or alzheimer\$.mp	206/212 (97.17%)	194/250 (77.6%)
		External Validation Set 452/517 (87.43%)	
PubMed Indexed Version	Dementia[mh] OR dement*[tiab] OR alzheimer*[tw]	206/212 (97.17%)	NA
Search Development in Non-indexed Set (PubMed)		"Lost Set"	Open PubMed – non-indexed
PubMed Non-indexed Version	Dement*[tiab] OR alheim*[tiab] OR Primary Progressive aphasia*[tiab] OR CADASIL[tiab] OR CARASIL[tiab] OR Creutzfeldt Jakob*[tiab] OR Frontotemporal lobar degenerat*[tiab] OR Huntington*[tiab] OR Kluver Bucy[tiab] OR Pick disease[tiab] OR Picks disease[tw] OR Pick's disease[tw] OR Primary Progressive Nonfluent aphasia*[tiab] OR sundown syndrome[tw] OR sundowning[tw] OR Korsakoff syndrome[tw] OR Binswanger*[tw] OR hiv associated neurocognitive disorder*[tw] OR cjd[tw]	629/1121 (56.11%)	207/250 (82.8 %)
Final Version for Use In PubMed (Indexed and Non-indexed Sets)			
Full PubMed Version	(Dementia[mh] OR dement*[tiab] OR alzheimer*[tw] AND Medline[sb]) OR ((Dement*[tw] OR alheim*[tw] OR Primary Progressive aphasia*[tw] OR CADASIL[tw] OR CARASIL[tw] OR Creutzfeldt Jakob*[tw] OR Frontotemporal lobar degenerat*[tw] OR Huntington*[tiab] OR Kluver Bucy[tiab] OR Pick disease[tw] OR Picks disease[tw] OR Pick's disease[tw] OR Primary Progressive Nonfluent aphasia*[tw] OR sundown syndrome[tw] OR sundowning[tw] OR Korsakoff syndrome[tw] OR Binswanger*[tiab] OR hiv associated neurocognitive disorder*[tw] OR cjd[tw]) NOT Medline[sb]) AND English[la]	NA	NA

Figure 1

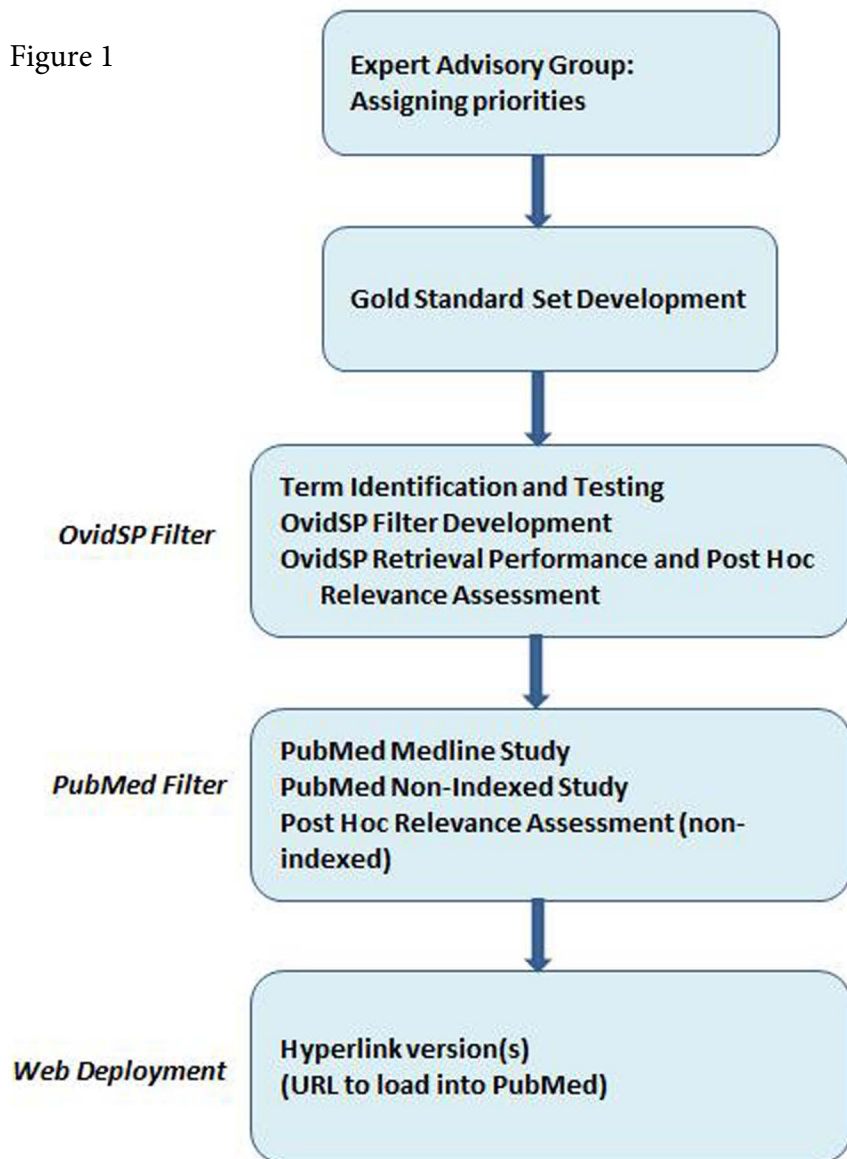


figure 2

Clinical Evidence

Advance Care Planning

Patient Management

Family and Carer Evidence

Service Delivery Evidence

Specific Diseases

> Dementia

- Palliative Care Challenges

- Caregivers and Care Settings

- Prognosis and Advance Care Planning

- Symptom Management

- Dementia PubMed Searches

- Create Your Own Dementia PubMed Search

- Information about Dementia PubMed Searches

> Heart Failure

> Lung Cancer Search Filters

You are here: [Clinical Evidence](#) » [Specific Diseases](#) » [Dementia](#) » [Dementia PubMed Searches](#)

Dementia PubMed Searches

The links on this page provide an easy, reliable way to find relevant dementia literature in English. Each link runs an immediate and up-to-date search of PubMed.

CareSearch search filters

These searches use the Dementia filter developed by CareSearch. It retrieves all English language articles of relevance to dementia within PubMed. You can run it alone or in combination with the CareSearch Palliative Care and Residential Aged Care Filters.

[Dementia](#)

[Dementia and Palliative Care](#)

[Dementia and Palliative Care in Residential Aged Care](#)

Dementia specific issue searches

Patient problems	Specific groups	Care issues
Agitation Everything Free full text only	Carers Everything Free full text only	Advance Care Planning Everything Free full text only
Anxiety Everything Free full text only	Aboriginal and Torres Strait Islander People Everything Free full text only	Advance Directives Everything Free full text only