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Filters and Hubs: Shortening the distance to palliative care evidence

Abridged Title: Filters and hubs

Abstract

Palliative care is an integral part of the care provided by GPs and other primary health care providers, and as Australia's population ages and the palliative care needs of patients with end stage organ failure are recognised, this area of care is likely to increase. Using a Knowledge Translation framework, two strategies have been used to develop resources to support those providing palliative care in the community. PubMed Searches on a range of common palliative care topics and incorporating a palliative care filter provide an easy and validated mechanism to retrieve relevant literature. A "GP Hub" offers knowledge, skills and practical advice for GPs who provide palliative care in the community. Both resources are freely available within the CareSearch website ensuring immediate access to palliative care information and evidence when it is needed.

Introduction

Primary care practitioners occupy a critical space in the healthcare system. They are the first point of contact for patients and provide direct care for a vast range of health needs within Australia's culturally and socially diverse population. As well, these health professionals provide a bridge to many other health and social services, and support public health and preventative health initiatives. The knowledge base that underpins general practice and primary health care is correspondingly large and complex. Therefore, providing knowledge infrastructure that enables those in primary health care to access needed evidence and guidance in a timely way is important.

While the web offers a mechanism for almost universal access, information resources need to be crafted to ensure that they are usable, relevant and trustworthy to the intended users. Knowledge translation frameworks provide a structure to ensure that issues around knowledge assembly and exchange are considered in the development of such resources. This article looks at resources developed as part of a national palliative care project that created "shortcuts" to enable use of palliative care's evidence base by all health professionals regardless of setting.

Context

The importance of palliative care within the health system has been increasingly recognised as Australia's population ages and the care requirements related to chronic and progressive disease grow in the community. National statistics indicate that, in 2009, there were more deaths from circulatory diseases than deaths from neoplasms and that heart disease, cerebrovascular disease, and dementia and Alzheimer's disease were the three most common causes of death. [Australian Bureau of Statistics, 2011] While palliative care has traditionally been seen as the management of the terminal phase of life, primarily caring for patients with advanced cancer, newer conceptions of palliative care highlight its role in maintaining quality of life through impeccable symptom management, support for psychosocial issues and advance care planning for all people who have a life-limiting illness. [World Health Organization, 2011; Palliative Care Australia, 2008] Hence, while Australian GPs have reported that they only manage three palliative care patients in a year [Mitchell, 2004], many other patients in their practice are likely to have palliative care needs such as those with end-stage organ failure [Murray 2008, Knapton 2010] or the frail aged [Hall et al, 2011]. At the same time, the management of many common cancers such as breast, colorectal, prostate, and even

lung cancer, is increasingly being shared with GPs who provide ongoing care for these patients in the community [Mitchell, 2008]. As a result, general practitioners and other primary care providers are increasingly, and inevitably, involved in providing care for those nearing the end of their life.

The Australian Knowledge Network in palliative care through its public portal the CareSearch website (www.caresearch.com.au) provides a focal point for quality palliative care information. It is a “safe place” for consumers to look for information and a trustworthy site for health professionals to recommend to patients and their families. Using Graham et al’s Knowledge to Action (KTA) Cycle (Figure 1) [Graham et al, 2006], the project has created structures and processes that consolidate the evidence and information base for health professionals and consumers as well as providing tools and resources to facilitate engagement within, and between, groups providing palliative care. The project seeks to support clinical practice by facilitating access to, and encouraging the use of, evidence as well as ensuring that patients, carers and families can easily find the information they need, when it is needed. Furthermore, a web presence means that CareSearch is readily and freely available throughout Australia seven days a week, twenty-four hours a day.

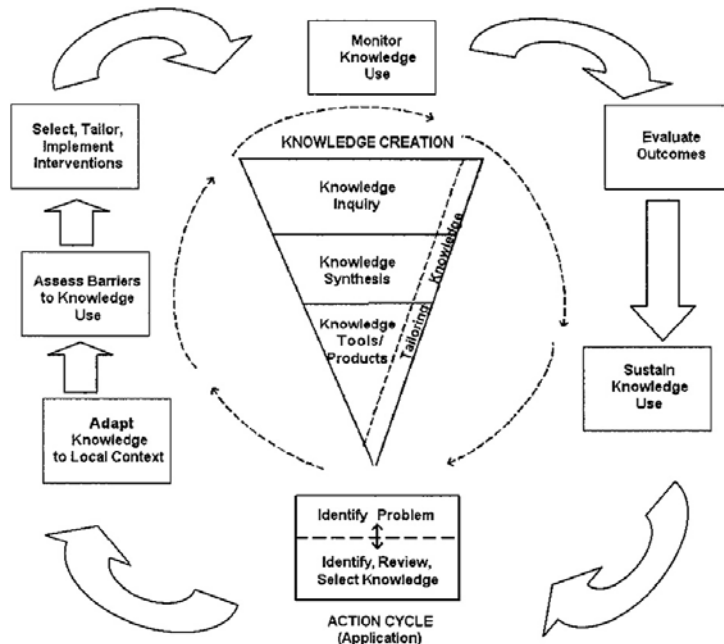


Figure 1: The Knowledge to Action Cycle

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Two strategies implemented by the project, search filters and professional hubs, utilise the capacity of the online environment to provide “shortcuts” to the evidence and to make

accessible practical palliative care resources that are useful for primary health care professionals. The strategies also demonstrate how the KTA Cycle has been used within the project as search filters can be seen as a knowledge product and the GP Hub as an application.

Review of relevant literature

Why a search filter?

Searching for relevant literature is a complex and difficult task made more difficult by a rapidly expanding evidence base and the skills required for effective searching. One study indicates that in the biomedical area there are now 75 trials and 11 systematic reviews being published each day and that the rate of growth of publication of clinical evidence may not yet have peaked. [Bastian et al, 2010] In palliative care, there has also been a significant increase in the absolute and relative volume of palliative care literature published on Ovid Medline from 1970 to 2005. Indeed, by 2005, one in every 122 clinical trials of all the trials published on Ovid Medline was to do with palliative or hospice care. [Tieman, 2008] This rate of knowledge production generally, and in palliative care specifically, has significant implications for the management of the knowledge base for professional practice and its currency.

Other work has shown that clinical and service information resides in scattered formats; that there is unique literature held in individual databases requiring searching of multiple databases; that articles can be inadequately indexed; and that effective literature retrieval requires time and sophisticated skills [Sampson et al, 2008; Tieman et al, 2008, Tieman et al 2009; Rankin et al, 2008, Tieman et al, 2010]. Further, different databases use different interfaces and default searching rules, making it unlikely that even experienced researchers will be both effective and efficient in finding all the literature they need. Poor searching can put the quality and authority of health and social guidance at risk, and errors in search strategies can reduce the value of the retrieved results. Even when high level searches have been written by experts, individual errors can remain. One study assessing searches written to support systematic reviews for the Cochrane Collaboration showed that 90% of these searches contained errors.[Sampson & McGowan, 2006] This error rate reflects the complexity of the process of constructing searches as well as the technical sophistication of the syntax used to interrogate specific bibliographic databases. Given experienced and trained searchers create searches with errors, it is likely that busy clinicians will also experience difficulties in developing effective searches.

Search filters offer a means to streamline searching and enable consistent and effective retrieval of relevant literature. Originally search filters were created to assist in the retrieval of articles reporting on research using a particular study design [Haynes et al 2005]. More recently, search filters have been developed to retrieve literature relating to a particular content area or topic such as renal studies [Iansavichus et al, 2010] or heart failure [Damarell et al, 2010].

Why a Hub?

Palliative care can be particularly daunting for some health professionals [Taubert & Nelson, 2005] and some GPs are reluctant to deliver palliative care [Rhee et al 2008]. Concerns reported by GPs included real and perceived work load demands, lack of support, and a lack of knowledge and confidence especially around technical skills and psychosocial issues [Mitchell, 2002; Reymond et al 2003].

While search filters may assist by automating the ongoing retrieval of emerging literature, primary health care professionals will still be challenged by the volume and diversity of the retrieved literature. The ability to incorporate evidence into practice depends not only on its accessibility but on its utility to the user and to the particular clinical need. Specific patient issues as well as the desire to maintain currency in practice knowledge have been shown to prompt doctors' use of the internet for information [Bennett et al, 2006]. However, information seeking can be affected by time constraints, lack of familiarity with resources as well as a lack of appropriate resources. A study of NSW GPs' use of, and barriers to using, evidence highlighted a lack of time, the lack of evidence, not knowing where to look and not being able to tailor evidence to individual patients as issues for GPs. The authors suggested that user friendly evidence summaries needed to be made available to assist those in general practice [Trevena et al, 2007].

Straus and Haynes have argued more broadly for more effective knowledge infrastructures to support health professionals [Straus and Haynes 2010]. They have stressed the importance of reliable, relevant and readable resources. Moreover, they have argued that a "5S" approach to evidence based health care with knowledge building from studies and syntheses through synopses and summaries to decision support systems would increase the value and usefulness of evidence.

Knowledge hubs that consolidate the relevant evidence and facilitate access to practical resources and relevant literature for specific professional groups offer one approach to organising evidence for use. Hubs are discrete sets of content and resources designed to

meet the information needs of a particular group or to accumulate the content base around a particular issue or care topic. Resources typically reflect the specific context or requirements of the professional group and information and resources are organised for easy and rapid use.

This approach to consolidating the resources for defined purposes is becoming more common and seeks to reduce the burden for the individual clinician associated with identifying, retrieving, sorting and appraising the relevance and quality of content. There a variety of approaches to knowledge infrastructures including discipline specific evidence resources such as OTSeeker [Bennett et al, 2007], practitioner led structures such as the Emergency Care Community of Practice [NHMRC, 2011] and professional development frameworks such as Cancer Learning [Cancer Australia, 2011]. An increase in palliative care resources has seen initiatives such as the Canadian Virtual Hospice [Canadian Virtual Hospice, 2011] and the End of Life Care for All learning resource (e-LFH, 2011) which seek to consolidate practice and academic knowledge around palliative care or an aspect of palliative care. However, given the multidisciplinary nature of palliative care, it can still be difficult for different professional groups to find information specific to their practice quickly and easily within such sites.

Outline of the practice innovations

Developing a palliative care search filter

A search filter is a tool to retrieve relevant literature of a particular study design such as a randomised controlled trial or on a particular topic such as heart failure. It is more than an expert search. Search filters are developed by determining the relative effectiveness of candidate searches in retrieving a gold standard set of articles known to be relevant to the topic of interest. Candidate searches are developed using index terms and textwords that have been identified through frequency analysis of abstracts, text or titles of relevant articles, and/or from reviews of database thesauri and from clinical recommendation.

The palliative care filter was developed using a dataset of palliative care articles identified through dual peer review of all articles published in four biomedical journals across three years [Sladek, Tieman et al, 2006]. The initial research was carried out in Ovid Medline and the search filter was subsequently translated for use in PubMed, the world's largest biomedical bibliographic repository [Sladek &Tieman, 2008]. PubMed has a number of practical advantages. It is free to search for citations and does not require payment or

registration. It also has a free full text limit enabling users to restrict retrievals to those articles available to view without fee or charge.

The practical effect of this translation to PubMed was to allow embedded hyperlinks representing the palliative care filter and the palliative care filter in combination with 60 palliative care topic searches to be held on a publicly available webpage. By clicking on the desired topic hyperlink, users can initiate the uploading of a search in the PubMed database, automatically running the search and retrieving relevant citations. (See Figure 2)

Clicking on this:

[Run palliative care filter now](#)

Loads this in PubMed to search for relevant citations:

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 1091-7683[is] OR 0030-2228[is]) NOT Medline[sb]) AND English[la]

Figure 2: Shows the embedded search that lies behind the hyperlink which is how the user activates the search

Creating the GP Hub

Given the specific involvement of primary healthcare in providing palliative care, priority was given to the development of a GP Hub within the CareSearch website. This Hub provides a direct entry point for GPs and enables rapid access to needed resources while still providing the capacity to extend their search back into the broader and more comprehensive evidence resources assembled in the website. This Hub consists of fifty-eight pages dealing with the practicalities of caring for palliative care patients in a community setting and addresses the most common care concerns identified by GPs [Sanderson, 2010]. Most pages dealing with a care topic have an associated 'More Information' page that provides links to further explanatory documents, suggests resources for use by the GP and the patient, and contains selected links to other bodies or agencies associated with the care issue.

The Hub was developed using the general framework of the KTA Cycle outlined in Figure 1. Specific KTA activities related to the GP Hub development are outlined in Figure 3. Consultations were held with GP organisations and the findings of two focus groups held with GPs on palliative care were reviewed. Searches were carried out in Medline and Informit to identify literature relating to GPs' palliative care information needs and for literature relevant to the Australian context and the online context. Web searches were conducted to identify relevant resources for potential inclusion. Ongoing feedback from practising GPs and user testing helped establish the most efficient presentation and layout of content. Formal content review was carried out by the National Advisory Group which comprises palliative care specialists, GPs, health professionals working in the community and patients and carers. This review enhanced the authority and relevance of the final content. A process for monitoring the use of the content was developed and strategies for ensuring the ongoing currency of the content and the resources were determined. The outcomes evaluation relied mainly on passive indicators of use such as web metric analysis and feedback responses to the content given anticipated problems in response rates to more formal survey mechanisms. [Bonevski et al, 2011; Harris et al, 2005]

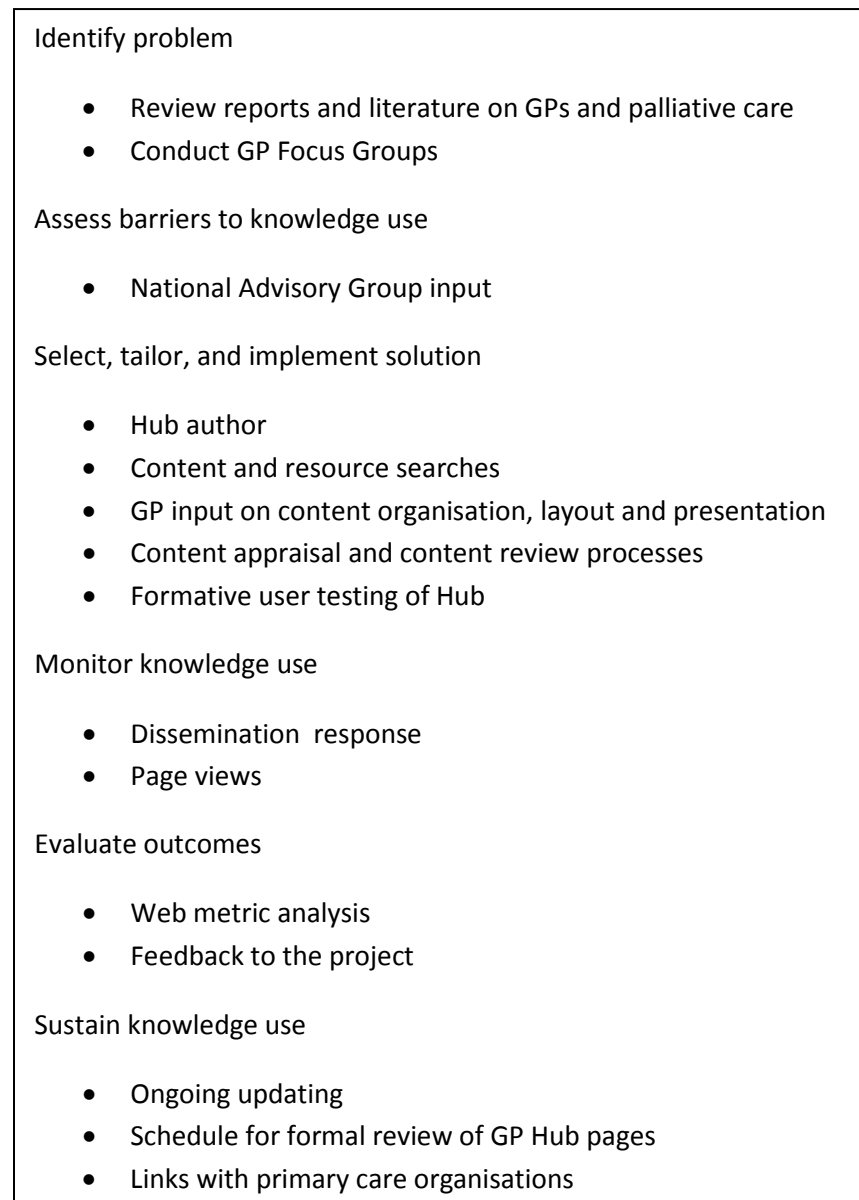


Figure 3: Overview of methodology to develop GP Hub

Project learnings

Formative evaluation activities such as user testing of the GP Hub prior to release were particularly valuable in refining both content and presentation prior to its release in May 2010. Feedback during the formative stage highlighted the importance of direct navigation and of content that addressed the actual processes and arrangements in general practice. Among a number of changes made to the Hub, the home page was modified to enable direct hyperlinking to each of the main topic areas within the Hub. Engagement with GPs during the developmental phase also highlighted a significant diversity in attitudes to palliative care provision among the participants and identified the need for graduated information to meet variations in knowledge across the main palliative care issues.

Web metrics indicate that there has been steady usage of the pages in the twelve months since their release. The analysis of page views downloaded from the site log of the website's content management system, (DNN Version 5.5) showed that from 1 July 2010 to 30 June 2011 there were 95,710 page views of the pages that formed the GP Hub. Page views do not include views of PDF documents held on the website and accessed by a link within the web page or external resources linked to from a hyperlink held on the web page; they are simply a count of the number of visits to web pages created for the GP Hub that were opened and viewed during the 2010-2011 financial year (Table 1). They are, therefore, likely to underestimate the actual number of resources that are being viewed through the GP Hub. There are 262 views of pages held within the GP Hub every day. Each individual page within the GP Hub is viewed on average 4.5 times daily. Importantly, analysis of views of topic pages within the GP Hub that had an associated 'More Information' page showed that these pages were been viewed around 20% of the number of times that the topic pages were being viewed (Table 1). This suggests that one in five users viewing a topic page are accessing more detailed information or further resources.

Interest and use of the GP Hub led to the subsequent development of a Nurses Hub which supports nurses providing palliative care in all settings of care. These pages complement material contained in the GP Hub and provide a stronger base for meeting the information needs of health care providers in the primary care environment.

Table 1: Page views 2010-2011, GP Hub	
Page	Requests
<i>Page views by topic area</i>	
GP Home	10,030
Patients Needing Palliative Care	18,131
Managing Symptoms	24,470
Making it Work in Your Practice	15,925
The Dying Patient	8,287
Following Up the Bereaved	4,770
Professional Development	6,503
GP Resources	7,594
Total page views	95,710
<i>Pages with "More Information" subpage</i>	
Page views of pages with More Information subpage	65,407
More Information subpage page views	12,679
Source: DNN Site Log downloaded on 6 July 2011	

During the same period from 1 July 2010 to 30 June 2011, there were 61,615 views of the pages containing the PubMed searches. It is assumed that most of these users would have activated at least one of the search options held on the page resulting in a search being uploaded and citations retrieved. Even if each page view was associated with only a single search being activated, the filter is supporting around 170 brokered searches for palliative care literature every day.

A study is currently underway with the aim of comparing the effectiveness of the palliative care filter in retrieving literature known to be relevant to palliative care with searches constructed by palliative care clinicians.

Conclusions

All health professionals face challenges in identifying and utilising literature and evidence that could inform their practice. For those working in primary care, there are further challenges relating to the range of care issues that GPs and other primary care professionals must address. Developing mechanisms to support these health professionals is therefore critical. Two strategies have been used to assist those working in primary care provide care to their patients who have palliative care needs. The first strategy was to broker access to palliative care's evidence base by making automated PubMed searches which incorporate the palliative care search filter available on the web. The second strategy was to create a "hub" within a palliative care website to provide GPs with profession specific content and enable rapid and direct access to relevant and trustworthy resources. Web usage data indicates that both these resources that are held on the CareSearch website are being used.

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