Not Published, Not Indexed: Issues in Generating and Finding Hospice and Palliative Care Literature

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Abstract

Introduction: Accessing new knowledge as the evidence base for hospice and palliative care grows has specific challenges for the discipline. This study aimed to describe conversion rates of palliative and hospice care conference abstracts to journal articles and to highlight that some palliative care literature may not be retrievable because it is not indexed on bibliographic databases.

Methods: Substudy A tracked the journal publication of conference abstracts selected for inclusion in a gray literature database on www.caresearch.com.au. Abstracts were included in the gray literature database following handsearching of proceedings of over 100 Australian conferences likely to have some hospice or palliative care content that were held between 1980 and 1999. Substudy B looked at indexing from first publication until 2001 of three international hospice and palliative care journals in four widely available bibliographic databases through systematic tracing of all original papers in the journals.

Results: Substudy A showed that for the 1338 abstracts identified only 15.9% were published (compared to an average in health of 45%). Published abstracts were found in 78 different journals. Multiauthor abstracts and oral presentations had higher rates of conversion. Substudy B demonstrated lag time between first publication and bibliographic indexing. Even after listing, idiosyncratic noninclusions were identified.

Discussion: There are limitations to retrieval of all possible literature through electronic searching of bibliographic databases. Encouraging publication in indexed journals of studies presented at conferences, promoting selection of palliative care journals for database indexing, and searching more than one bibliographic database will improve the accessibility of existing and new knowledge in hospice and palliative care.

Evidence-based practice assumes that:

- Clinicians can access the literature and having accessed the literature, are able to synthesize the literature; or
- Clinical guidelines and systematic reviews include all research relevant to the clinical question.7

Publication and subsequent indexing represent pivotal steps within the spectrum of disseminating new knowledge. Electronic bibliographic databases are significant components of this knowledge infrastructure, providing clinicians and academics with the capacity to easily engage with the literature. However, it is important to recognize that such databases do not contain all possibly relevant literature and that there are known limitations associated with publishing and indexing processes which in turn limit access to the whole knowledge base that could inform clinical decision-making.

Introduction

Recent studies suggest that hospice and palliative care’s literature base is developing strongly.1,2 The absolute number of hospice and palliative care citations is increasing as is the proportion of hospice and palliative care citations as a fraction of all published papers. Hospice and palliative care clinical trials indexed on Ovid MEDLINE are also increasing at a higher relative rate than Ovid MEDLINE as a whole.1

Access to this literature is important not only for individual practitioners in clinical decision making but for the academic discipline of hospice and palliative care in developing its fields of enquiry.3,4 At times, it is assumed that identifying this literature is straightforward, but as the source literature is systematically mapped, it is evident that it is widely dispersed across the refereed literature.1,5,6

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It is important that sources of “missing” hospice and palliative care literature are identified and quantified in order to encourage maximum inclusion and assess the relative importance of possible losses.

In particular, known gaps in the aggregated biomedical literature include:

1. Research work that will never be published in journals.8–11
2. Journals that are not indexed on major bibliographic databases such as MEDLINE, Embase, or CINAHL.12–14
3. An expected lag time between when a journal is first published and when it is selected for indexing.15
4. Idiosyncratic omissions from the indexing process even when a journal is included in electronic bibliographic databases.16

Many publishing and indexing issues are not widely understood and the impact of them on the evidence base is poorly quantified. However, separately and collectively these systematic and ad hoc omissions could reduce the available literature to inform the evidence base of hospice and palliative care.

The aims of these two substudies are to describe conference conversion rates that may influence information dissemination and to highlight indexing considerations, two key aspects of information loss.

Methods

CareSearch (www.caresearch.com.au) is a project funded by the Australian Government to support health professionals by providing access to evidence for hospice and palliative care. As part of this project, work has been undertaken to identify sources of “missing” literature17 and to locate, and make available to the clinical and research community, literature and evidence that may otherwise be unavailable electronically.

Substudy A: Conference abstracts to journal article conversion study

Conference abstracts are one of four gray literature collections held within CareSearch.18 To be included in the CareSearch repository, these abstracts have been reviewed for relevance to hospice and palliative care and include sufficient detail of results to suggest the study was likely to have been completed.

To locate possible conference abstracts, organizations hosting conferences likely to include presentations of relevance to hospice or palliative care were contacted and asked for conference proceedings and for permission to host all selected abstracts in the CareSearch database.

The abstracts presented at more than 100 conferences in Australia between 1980–1999 were reviewed (Table 1). Two senior palliative care clinicians independently hand searched all conference proceedings and assessed abstracts for relevance to palliative care. Disagreements were settled by consensus.

Following this process of identification and review, 1338 conference abstracts for the period 1980–1999 were selected for the CareSearch database. This set of 1338 conference abstracts was used in the study to determine the conversion rate from date of conference presentation to journal publication by 2004. Although abstracts for conferences after 1999 continue to be reviewed and included in the database, the set for the study only used conference abstracts presented up to and including 1999. This break of 5 years from 1999 to 2004 was chosen arbitrarily to optimize the likelihood of conversion to

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**Table 1. Organizations that Provided Consecutive Conference Proceedings Books for Evaluation for Palliative Content, the Years Covered, and the Frequency of Conference**

<table>
<thead>
<tr>
<th>Organization</th>
<th>Conference</th>
<th>First year collected</th>
<th>Frequency of conference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Association of Australia</td>
<td>National Conference</td>
<td>Since 1994</td>
<td>Annual</td>
</tr>
<tr>
<td>Australian New Zealand Society of Palliative Medicine (ANZSPM)</td>
<td>Conference and Scientific Meeting</td>
<td>Since 1994</td>
<td>Even years</td>
</tr>
<tr>
<td>Australasian Society for HIV Medicine (ASHM)</td>
<td>Annual Medical and Scientific Conference</td>
<td>Collected from 1990</td>
<td>Annual</td>
</tr>
<tr>
<td>Australian Association for Hospice and Palliative Care/ Palliative Care Australia (PCA)</td>
<td>National Conference</td>
<td>Since 1993</td>
<td>Odd years</td>
</tr>
<tr>
<td>Australian Pain Society</td>
<td>Annual Scientific Meeting</td>
<td>Since 1980</td>
<td>Annual</td>
</tr>
<tr>
<td>Cancer Nurses Society of Australia</td>
<td>Winter Congress</td>
<td>Since 1999</td>
<td>Annual</td>
</tr>
<tr>
<td>Clinical Oncological Society of Australia (COSA)</td>
<td>Annual Scientific Meeting</td>
<td>Collected from 1982</td>
<td>Annual</td>
</tr>
<tr>
<td>One off and ad hoc conferences</td>
<td>Palliative care education</td>
<td>Various dates</td>
<td>Intermittent</td>
</tr>
<tr>
<td>Palliative Care Queensland</td>
<td>State Conference</td>
<td>Since 2000</td>
<td>Even years</td>
</tr>
<tr>
<td>Palliative Care Victoria</td>
<td>Palliative Care Victoria Conference</td>
<td>Since 1999</td>
<td>From 2000</td>
</tr>
<tr>
<td>Royal Australasian College of Physicians</td>
<td>Annual Scientific Meeting</td>
<td>Collected since 1981</td>
<td>Annual</td>
</tr>
<tr>
<td>Rural Palliative Care Group of South Australia</td>
<td>Annual conference</td>
<td>Since 1992</td>
<td>Even years</td>
</tr>
<tr>
<td>Western Australia Hospice Palliative Care Association Inc</td>
<td>State Conference</td>
<td>Since 1998</td>
<td>Even years</td>
</tr>
</tbody>
</table>
publication given the time required for preparation, drafting, peer review, and publication.

Data items entered on an Excel spreadsheet included conference source, year of presentation, number of authors noted on abstract, number of institutions involved in the study, and the type of presentation (plenary, oral, workshop or poster). To determine if an abstract had been published included abstract details (names of presenting author(s), text words from the title and abstract, and appropriate index terms for the content) were used to search four electronic bibliographic databases—Ovid MEDLINE, CINAHL, Embase, and PsycINFO. Retrieved citations were compared to the original conference abstract to determine if it was the same body of work.

Citation details of published articles were added to the spreadsheet. The journals within which the associated papers were published were allocated to broad domains based on the purpose and readership of the journals.

Substudy B: Indexing

A list of hospice and palliative care journals was developed as part of the project’s initial activities based on a search of Index Medicus (MEDLINE’s now discontinued journals listing), discussions with librarians and suggestions from the project’s National Reference Group. From this list, three journals were selected for the indexing study in December 2002:

1. Palliative Medicine
2. Journal of Palliative Medicine
3. International Journal of Palliative Nursing

These journals were selected for the study because they reflected a multidisciplinary approach to care, needs-based rather than disease-based scope and coverage of both Europe and North America. Date of first publication and date of journal indexing in each database were determined by reference to the individual bibliographic database’s journal listings.

An Excel spreadsheet of refereed articles in each issue for each journal from first publication until 2001 was also created. Items that were editorial policies, conference and research abstracts, journal abstracts, product news, meetings and events, and book reviews were all excluded.

Each article citation was then individually searched for using author and item title in each of four bibliographic databases—Ovid MEDLINE, CINAHL, Embase, and PsycINFO—to determine if it was included in that database.

Results

Substudy A: Conference abstracts to journal article conversion study

The conference conversion study found that only 213 of the 1338 (15.9%) of conference abstracts had been published in one of the journals indexed on the four major bibliographic databases. The publication rate within years varied from 0% to 100%. Figure 1 shows comparatively the number of conference abstract presentations and the number that have been published by year of initial presentation where more than 10 papers were identified.

The 213 published articles were found in 78 separate journals. Fourteen percent of articles were published only in an Australian journal. Of the papers that were published, only one third that had previously appeared as conference abstracts were found in specialist hospice and palliative care journals, with others spread across a wide number of journals in a range of domains (Table 2).

<table>
<thead>
<tr>
<th>Journal domain</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist palliative (medicine and nursing)</td>
<td>70</td>
<td>32.9%</td>
</tr>
<tr>
<td>General medical</td>
<td>47</td>
<td>22.1%</td>
</tr>
<tr>
<td>Other medical specialty</td>
<td>57</td>
<td>26.8%</td>
</tr>
<tr>
<td>Other nursing</td>
<td>18</td>
<td>8.5%</td>
</tr>
<tr>
<td>Allied health</td>
<td>1</td>
<td>0.5%</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>20</td>
<td>9.4%</td>
</tr>
<tr>
<td>Total</td>
<td>213</td>
<td>100%</td>
</tr>
</tbody>
</table>
Type of presentation and subsequent publication: Workshops had the lowest conversion to publication rate of 6.5% and oral presentations had the highest rate at 17.4%. Publication rates for posters and plenary sessions were 14.3% and 14.8%, respectively.

Number of authors and subsequent publication: Conference presentations with a single author only had a conversion to publication rate of 10% while multiple authors more than doubled the likelihood of publication to 24%.

Substudy B: Indexing

Twelve hundred and fifty-three articles were published in the three journals by the end of 2001. The indexing study shows that there is a more than 3-year lag time between first publication and MEDLINE journal indexing for all three journals and that the Journal of Palliative Medicine and the International Journal of Palliative Nursing were both indexed first by a database other than MEDLINE (Table 3).

Once the journals were indexed, Table 4 identifies the possible size of the indexing loss for these journals, individually and collectively, before and after listing. By 2001, of the 1253 referred articles published in the three journals only 661 (53%) were indexed in MEDLINE. Importantly, Table 4 also shows that more comprehensive retrieval of the items would have been achieved by combining searches in all four bibliographic databases in which 973 items (78%) of the collection would have been retrieved. Effectively, early indexing of International Journal of Palliative Nursing by CINAHL and Journal of Palliative Medicine by Embase made the content available to researchers and clinicians who had access to these particular bibliographic databases (Fig. 2).

Discussion

These studies add to what is known about “blind spots” in retrieving hospice and palliative care literature. They highlight previously unknown and unquantified sources of information loss for this field. Earlier work has already shown

<table>
<thead>
<tr>
<th>Journal</th>
<th>First published</th>
<th>MEDLINE</th>
<th>Embase</th>
<th>CINAHL</th>
<th>PsychINFO</th>
</tr>
</thead>
</table>


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Table 4. Individual and Summary Figures for Journals: Number of Articles, Number Indexed in Medline, and Number Indexed on Any of Four Databases—Medline, Embase, PsycINFO, CINAHL

<table>
<thead>
<tr>
<th>Year</th>
<th>PMa PMb IJPNc ALLd</th>
<th>PMa PMb IJPNc All</th>
<th>All Medline</th>
<th>All Medline/ALL %</th>
<th>IJPNc PMa PMb PMc PMd</th>
<th>All indexed</th>
<th>All indexed/ALL %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1987</td>
<td>21</td>
<td>0</td>
<td>0</td>
<td>59</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1988</td>
<td>24</td>
<td>0</td>
<td>0</td>
<td>56</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1989</td>
<td>20</td>
<td>0</td>
<td>0</td>
<td>57</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1990</td>
<td>38</td>
<td>0</td>
<td>0</td>
<td>67</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1991</td>
<td>45</td>
<td>0</td>
<td>0</td>
<td>71</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1992</td>
<td>38</td>
<td>0</td>
<td>0</td>
<td>77</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1993</td>
<td>51</td>
<td>0</td>
<td>0</td>
<td>86</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1994</td>
<td>47</td>
<td>0</td>
<td>0</td>
<td>99</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1995</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1996</td>
<td>57</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1997</td>
<td>57</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1998</td>
<td>65</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1999</td>
<td>24</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2000</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2001</td>
<td>58</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>ALL</td>
<td>749</td>
<td>168</td>
<td>336</td>
<td>1253</td>
<td>530</td>
<td>83</td>
<td>661</td>
</tr>
</tbody>
</table>
the challenges clinicians confront given the diverse range of journals publishing palliative care literature and the difficulty in comprehensive and precise retrieval using electronic search strategies. These two studies demonstrate that information “loss” can occur when:

1. Research is not published;
2. Research is published in journals that are not selected for journal indexing on bibliographic databases;
3. Searching is restricted to a single bibliographic database as databases differ in their journal inclusion strategies, and
4. Indexing processes and policies affect complete table of contents indexing (e.g., supplements are not indexed, in progress indexing, idiosyncratic omissions, etc.).

While the two studies have shown that such losses occur, the impact of such losses on the evidence base for palliative care can not be determined from these studies. However, other work has looked at the effect of information losses generally and in other disciplines. A Cochrane review has shown that published trials show an overall greater effect than trials captured only in the gray literature, thereby introducing bias when only published studies are included in reviews. Trials with neutral or negative findings take longer to publish which introduces a more subtle source of publication bias. A 2006 analysis of acute stroke trials showed a significantly greater proportion of harmful outcomes in unpublished studies compared with published trials. Hence relying on published indexed work alone may bias findings and potentially clinical decisions.

Substudy A highlights the need for further work to understand why presented work is not being published. In the interim, gray literature repositories such as the CareSearch Grey Literature and hand searching of conference abstract reports in relevant journals may help ensure that any missing literature is captured. The importance of hand searching for comprehensive retrieval has been recognized for similar reasons in a recent Cochrane review.

Indexing is an organic process with journals being added and removed constantly. MEDLINE’s own FAQ on journal selection notes that while there are approximately 14,000 biomedical titles only approximately 5300 titles are currently indexed in MEDLINE. Furthermore, only 20%–25% of titles submitted for review are selected for indexing.

Substudy B demonstrates that in palliative care, as in other fields, publishing in a journal does not necessarily mean automatic inclusion in MEDLINE. For the three journals studied, the lag time between first publication and first indexing on MEDLINE was between 3 and 6 years. While content may subsequently be retrospectively indexed, these time lags still represent an effective loss of accessibility to new knowledge.

Substudy B also showed that all three journals were indexed on more than one database and that relying on a single database to look for material from first publication to 2001 could have resulted in nonretrieval of up to 75% at different time points. As such, searching in more than one database would have retrieved more of the items in the three journals for 7 of the 9 years in which the journals were indexed. This supports the findings of a recent bibliometric study identifying the proportion of unique hospice and palliative care literature on CINAHL, Embase, and PsycINFO compared to MEDLINE.

It is also worth noting that even after a journal was selected for database indexing not all items were indexed as some citations simply never appear (Fig. 2). This is likely to reflect the individual indexing processes of bibliographic databases. For example, reports included in journal supplements are not routinely indexed on MEDLINE.

Substudy A highlighted the broad number of potential journals hosting hospice and palliative care literature. Published abstracts were found in 78 journals; only a third of the papers were published in specialist hospice and palliative care journals. While not surprising because hospice and palliative care literature reflects the many contributing disciplines, specialties, and professions engaged in caring for people with progressive life-limiting illnesses, the complexity of the care needed and the different settings of care delivery, it reinforces that finding hospice and palliative care literature is a complex activity.

Limitations

Publication is expected to take some time given write-up, peer review processes, proofreading, and printing. Even the
5-year window in substudy A to ensure that every opportunity for conversion from abstract to peer-reviewed publication was allowed may not have been sufficient. The conference conversion study used a convenience sample of conference abstracts. They do not represent a set of abstracts from a single palliative care conference but were identified from diverse conferences which may introduce unknown bias into the conversion rate. However included items were from conferences that were seen to be potentially relevant to hospice and palliative care and had been reviewed for inclusion by clinical specialists. There is also no way of quantifying the number of authors who prepared work for publication but had the submission rejected or of identifying presentations that were published in nonindexed journals.

Indexing is a dynamic process. Access to content will change as journals are added (or removed) and as content is retrospectively added to the index. There is also a time gap between when journal articles are published and when the mechanical or electronic processes of including citation details and index terms is completed and the full record available within the bibliographic database for searching. This was dealt with by leaving at least 3 years between the last data point and the first evaluation of electronic bibliographic citations in substudy B.

**Future research directions**

There is an urgent need to understand why hospice and palliative care researchers and clinicians do not publish their findings. Not submitting work for publication fails to expose researchers in this discipline to the review provided by their peers, and also fails to share findings with their colleagues around the world that could be more broadly applied to clinical practice or policy. This suggests that there may be significant clinical and service knowledge that cannot be accessed and evaluated for integration into practice. Furthermore, doing a study, using resources including the time and good will of participants and not publishing in peer-reviewed literature is ethically unacceptable particularly in the hospice and palliative care populations.

Determining conference conversion rates for conferences in other countries and whether the publication rate is increasing over time would be valuable. It would also be useful to ascertain relative conversion rates for hospice and palliative care work presented at specialist palliative care conferences, other specialty conferences and generalist conferences.

There is a need for detailed work around journal indexing. Identifying journals publishing palliative care research and if, and where, they are indexed is important if all clinical findings are to be included in decision making. The three journals investigated in the indexing substudy were a cross section of key hospice and palliative care journals. The same methodology could be used to test other hospice and palliative care journals.

**Implications for practice**

Searching effectively is a highly specialized field and a systematic approach is needed. Researchers and clinicians need to be familiar with the structures, processes, and limitations of the individual bibliographic databases and be aware that potentially relevant literature exists outside of these databases. Making use of gray literature sources, hand searching tables of contents, and checking conference proceedings could also capture missing work.

Researchers and clinicians need to be encouraged to publish their research work and to publish it in indexed journals. There is also a need to support journal publishers submitting nonindexed palliative care journals for indexing review to facilitate electronic retrieval of hospice and palliative care literature.

The wide array of journals in which key hospice and palliative care literature is published is staggering. It will continue to challenge the ability of the whole field to integrate existing knowledge into a meaningful and coherent corpus. Searching more than one database is likely to lessen poor retrieval practices and increase yields. When comprehensive retrieval is needed for clinical or academic purposes, seeking assistance from those with specialist searching skills such as expert health librarians or utilizing validated search strategies will also improve results.

**Conclusion**

Not all research work and new knowledge within hospice and palliative care is converted to journal articles and published. Journal indexing does not equate with indexing all contents of all listed journals. There are journals that are not yet, or may not ever be, indexed on a major bibliographic database. Ensuring that clinicians and researchers are able to access all literature is as important as carrying out the research to develop this evidence.

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**Author Disclosure Statement**

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