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Multiple sources: mapping the literature of palliative care

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Palliative care is an increasingly important area of clinical practice and health service delivery. The heterogeneity of the patient population and the multidisciplinary nature of care draw on knowledge from many fields of clinical practice and academic enquiry. This has implications for the retrieval of evidence and literature and the spread of new knowledge in palliative care. This study shows that the CINAHL, Embase and PsycINFO bibliographic databases hold sizeable repositories of palliative care articles not indexed on Medline. It also highlights the number and range of journals publishing palliative care content. In 2005 alone, 1985 journals published 6983 items. These findings show the challenges for palliative care professionals in managing the complex evidence base for this diverse field of care and the importance of mechanisms that facilitate the identification of palliative care information. Dissemination strategies that ensure that new knowledge reaches the many audiences implicit in the range of journals publishing palliative care are also critical in supporting improvements in clinical practice and service delivery. *Palliative Medicine* (2009); **00**: 1–7

Key words: bibliographic; databases; hospices; information dissemination; palliative care; publishing

Introduction

Palliative care emerged as a new discipline in the second half of the last century and began a period of growth and change.[1] Changes included a subtle but important move in orientation from medical anecdote and personal experience to evidence and the transition of provision of care from charitable organisations to the modern welfare state in many countries.[2] The growing interest in and support of palliative care was reflected in the establishment of the world's first modern hospice, St Christopher's, in London in 1967.[3] Since then, palliative and hospice care has developed rapidly. Recently, it was reported that around 50% of the world's countries representing 88% of the global population have at least one hospice-palliative care service.[4]

The literature that supports this discipline is complex, reflecting changing and dynamic information and evidence needs that could modify the clinical course of co-morbid or life-limiting illnesses.[5] The field is not limited by a single diagnosis, symptom or population characteristic and therefore has a marked heterogeneity in practice areas. As a discipline, it intersects other medical specialties and academic disciplines, both drawing from their literature and potentially contributing to their practice.

Accessing literature is integral to evidence-based practice, yet searching for palliative care literature can be difficult.[6,7] It is published in specialist and non-specialist journals covering disciplines such as psychology, medicine, nursing and social work.[8] Successful searching may depend on how journal articles are indexed and the structure of databases[9] as well as the individual searcher's skills and knowledge.

Conversely, appropriate dissemination of new knowledge is seen as integral to knowledge translation. Ensuring that new practice and research evidence is made available to the intended users of this knowledge forms part of the cycle of moving evidence into use.[10] For a multidisciplinary field such as palliative care that engages with academics and researchers across a range of disciplines and with health professionals in diverse sites and settings of care, communication is fundamental. Appropriate publication in journals relevant to these participants can provide access to the developing knowledge base.

A more accurate understanding of the nature of palliative care literature would have many benefits. First, it could inform our search processes. Second, it could help develop appropriate literature collections for clinical, research and academic institutions. Third, it could assist researchers in finding suitable journals for publication. Fourth, it could help plan for knowledge dissemination. Fifth, it could document the state of the knowledge base for palliative care practice and highlight issues associated with managing this resource. Finally, it could help to identify areas for future research and collaboration.

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This work is part of a larger project looking at the evidence base for palliative care and how to make it available to the clinical and patient community.[11]

In this study, the sources and changes over time of literature relevant to palliative care are explored. Specifically, two questions were investigated:

1) What has been the absolute unique growth over time in relevant citations on CINAHL, PsycINFO and EMBASE when each is compared with Medline respectively?
2) Using a range of major bibliographic databases, which indexed journals are publishing literature relevant to palliative care?

Methods

OVID versions of all databases were used except where stated and searching completed during July–August 2007. Details were recorded and analysed using an Excel spreadsheet. The search strategy used to identify relevant palliative care literature was the Boolean expression (palliat$ or hospice$ or 'terminal care').af. (we refer to the results of this search as the 'palliative search'). Although not a highly sensitive search, it offers several benefits. First, this combination of terms has been used previously to examine the coverage of relevant literature in databases.[12,13] Further, in an initial study validating a palliative search filter, this phrase was found to have a specificity of 99.97%.[7] Such high specificity provides confidence that citations retrieved are truly palliative in nature. Second, textwords (rather than subject headings) enabled a search of multiple databases and a comparison of the results without concern for different thesauri used by different databases. Third, this avoided searching complexity that would otherwise be involved by the evolution of thesaurus terms within each database over time.

To assess the unique relevant literature indexed in each database (EMBASE, PsycINFO and CINAHL) in addition to Medline citations, the palliative search was first run in Medline using each of five yearly cutoff points. By using OVID's multi-file search option functionality, each search was subsequently run on OVID EMBASE, PsycINFO and CINAHL. To identify the unique contribution for each of these three bibliographic databases, duplicate citations (those already indexed on Medline) were removed using the 'deduping' function of the software. This provided the total number of citations indexed on each database that were not indexed on Medline and hence were unique and additional to the Medline coverage. Deduping also removed duplicates that exist within a database.

To look at which journals are publishing the majority of palliative care literature, an investigation of multiple bibliographic databases was undertaken for three publication years – 1995, 2000 and 2005. A corresponding EndNote file was created for each year. Searches of key bibliographic databases were then undertaken, restricted to the year of publication, using the palliative search. The following databases were included: OVID Medline, EMBASE, PsycINFO, Biological Abstracts, CINAHL, Ageline, EconLit and Eric, and all databases in AustHEALTH. EndNote files were created with an instruction for duplicates to be removed as records were imported. Additionally, two reviewers checked the files manually to identify further duplicates. All references to non-journal citations (e.g., books, book chapters, newspaper articles, reports and theses) were removed. Files were then ordered according to journal name and frequencies calculated.

Results

Analysis by database

The total number of palliative citations within each database by 2005 was 56,039 (Medline), 32,945 (EMBASE), 22,136 (CINAHL) and 8426 (PsycINFO). The number of citations grew in each 5-year period in each database from 1960 (Table 1).

Table 1 Growth in all citations and deduped citations: Ovid Medline, Embase, PsycINFO and CINAHL (till 1945 to 2001–2005)

	Till 1945	1946–1950	1951–1955	1956–1960	1961–1965	1966–1970	1971–1975	1976–1980	1981–1985	1986–1990	1991–1995	1996–2000	2001–2005	Total
Medline all	0	25	63	111	456	1267	2088	3541	4676	6644	9003	12,332	15,833	56,039
CINAHL all	0	0	0	0	0	0	0	2	527	678	2363	6615	11,951	22,136
EMBASE all	0	0	0	0	0	0	0	691	2486	2953	4949	8258	13,608	32,945
PsycINFO all	27	11	8	4	2	15	20	46	211	516	656	1452	5458	8426
Medline deduped	0	25	62	111	449	1256	2075	3516	4655	6622	8981	12,285	15,716	55,753
CINAHL deduped	0	0	0	0	0	0	0	2	269	372	1742	5095	8652	16,132
EMBASE deduped	0	0	0	0	0	0	0	338	1015	1024	2625	4453	7019	16,474
PsycINFO deduped	27	11	8	4	2	14	16	24	124	288	303	1048	3926	5795

After deduping processes, the unique palliative citations found in each database (i.e., not also indexed in Medline) were 16,474 (EMBASE), 16,132 (CINAHL) and 5795 (PsycINFO). In other words, 50.0% (16,474/32,945) of the retrieved EMBASE records were unique, 68.8% (5795/8426) of PsycINFO and 72.9% (16,132/22,136) of CINAHL records. Again, citation counts increased for the deduped records in each 5-year period in each database from 1960 (Figure 1).

Importantly, the relative contribution of deduped material for each database as a proportion of the joint citation contribution with Medline increased over each 5-year period (Figures 2 A–C). Therefore, EMBASE, CINAHL and PsycINFO are increasing the amount of unique material that cannot be retrieved through Medline over time.

Analysis of indexed journals

The analysis of records retrieved by the palliative search in eight databases for the three discrete years shows that both the number of citations and the number of journals publishing these citations rose. In 1995, 1010 journals published 3058 citations and in 2005 this was 6983 citations in 1985 journals (Table 2). Approximately half of the journals had only one palliative care article in a given year. To capture half of the palliative care literature, you would have needed to harvest from over 100 journals and this number increased over the period. Figure 3 graphically shows the number of journals required to capture 25, 50, 75 and 100% of citations for each of the 3 years.

Journals were ranked in descending order according to the number of palliative citations published in that year. Based on this ranking, journals were selected to create a set comprising 25% of all citations. In all, 46 journals were in this 25% in any of the 3 years. There were 29 journals in 1995, 24 journals in 2000 and 31 in 2005. In all, 16 of these were common for all 3 years, a further 10 were found in 2 years, whereas 20 journals were in this 25% in only one of the 3 years (Table 3). Of the 16 journals common to all 3 years, five could be seen as specialist palliative care (e.g., *Palliative Medicine*), five as oncology (e.g., *Annals of Oncology*), four as nursing (e.g., *Journal of Advanced Nursing*) and one as general medical (*British Medical Journal*). Four of the 46 journals were published in a language other than English. The broader set of journals also includes titles such as Home HealthCare Nurse and Caring that reflect a more vocational publishing role.

Discussion

The study shows that there is a substantial and increasing amount of palliative care literature. A three-term palliative search in four bibliographic databases retrieved approximately 120,000 citations. Nearly 60,000 of these citations were indexed in Medline. However, CINAHL, EMBASE and PsycINFO collectively housed around 40,000 citations not indexed on Medline.

Finding a large amount and increasing amount of unique literature in each of the databases is important, given the particular collecting emphasis of the individual databases (CINAHL focuses on nursing and allied health,[14] PsycINFO on psychological and behavioural fields[15] and EMBASE on pharmacotherapies[16]). Approximately 40% of the unique literature would not have been retrieved if the search was carried out in Medline alone. Although we did not determine the material held exclusively in each database, given the specific collecting emphases, it is likely that a large proportion of the non-replicated material remaining after deduping against Medline is likely to be found in only one database.

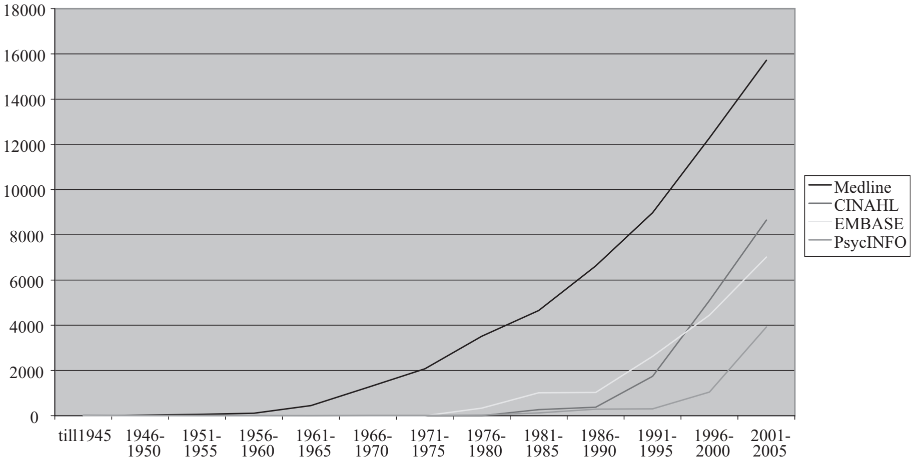

Figure 1 Unique contribution of databases (Deduped against Medline): number of citations in 5-year periods.

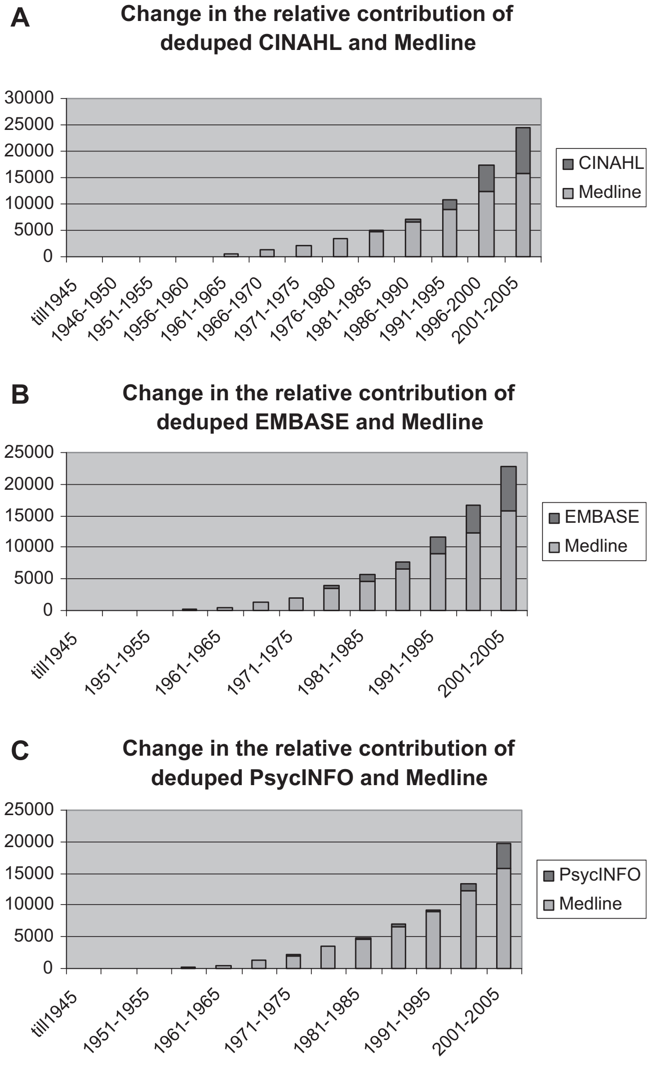

Figure 2 Changes in the relative contribution of unique material of the combined citations of the individual databases and Medline over time.

Seeking relevant literature in as many databases as possible may be important to ensure comprehensive palliative coverage. Given the role that journal publication plays in the spread of knowledge and ideas, this study also validates the academic and professional contributions that the non-medical disciplines are making to the development of palliative care.

Identifying journals that publish palliative care literature is an important step in understanding the sources of information and the avenues for knowledge dissemination. The rise in both the number of journals and the number of citations relevant to palliative care for 1995, 2000 and 2005 suggests that palliative care is an area of increasing academic and clinical interest and activity. This may reflect the growing importance of palliative care to the community and for the health system as the health care needs of the aged and those with chronic diseases emerge.

Bradford's Law of Scattering suggests that a relatively small proportion of core journals account for a disproportionate amount of the literature, meaning that over time literature consolidates into a known group of journals.[17] Although this study shows that there is a tendency for a core set of journals, it is a relatively large group with 46 journals identified as contributing 25% of the articles in any of the 3 years of analysis. It may be that a core set of journals is still evolving or that given the diffuse and multidisciplinary nature of palliative care study and practice there will always be a complex set (or group of subsets) of core journals. The number of journals contributing any material is also growing from a relatively large base highlighting the complex nature of the palliative care literature base. This has implications for retrieving and communicating evidence. For example, the large number of journals publishing more than 10 articles a year may reflect the disciplines and fields for whom palliative care is a small but still significant part of their practice such as general practitioners (GPs) or geriatricians.

The diversity of the journals contributing 25% of the palliative care literature again shows the diverse nature of palliative care. The journals span disciplines such as nursing, geriatrics and medicine as well as medical specialties such as palliative medicine, oncology, general medicine and thoracic surgery. All these journals are publishing a significant number of palliative care articles indicating that palliative care is an important part of their practice. Journal type also highlights the significance of literature not only as a vehicle for research publication but also as a mechanism for the dissemination of practice information. Vocationally ori-

Table 2 Citation numbers and journal numbers retrieved by palliative search by year of analysis

	1995	2000	2005
Number of citations	3058	4244	6983
Number of journal titles	1010	1361	1985
Mean citations per journal	3.03	3.11	3.49
Number of journals one citation only	530	759	994
Number of journals ≥10 citations	57	78	122
Number of journals indexing			
25% of citations	29	24	31
50% of citations	120	127	179
75% of citations	364	451	615

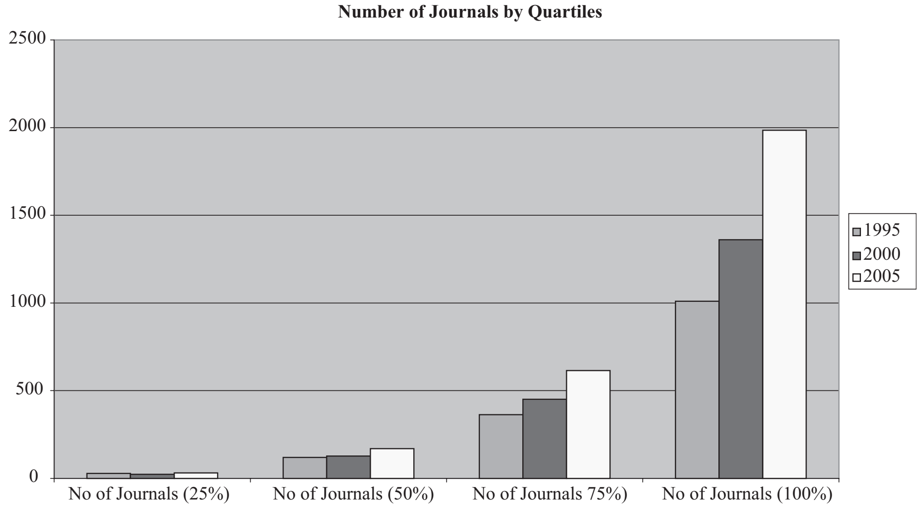

Figure 3 Number of journals by largest number of citations holding 25, 50, 75 and 100% of palliative care citations in 1995, 2000 and 2005.

ented titles such as Caring and Home Healthcare Nursing highlight the need to ensure that research evidence is disseminated and communicated appropriately to all those involved in providing care.

This journal publication pattern shows that the sources of palliative care information are multiple. This reflects both the diversity of knowledge needs for palliative care specialists as well as the specific needs of providers such as GPs or oncologists and the impact of site of care such as residential aged care facilities. Given that comprehensive care addresses physical, psychological and social needs,[18] knowledge from a range of academic disciplines such as psychology, social work, nursing and medical specialties needs to be incorporated. Palliative care is the major focus of work for some health professionals but only an intermittent or minor part of practice for others. Palliative care may be part of the continuity of care provided for patients in the primary care setting or it may need specific care in specialist practice areas such as physiotherapy or social work. Therefore, these professionals may have specific information needs as well as knowledge and evidence to share.

Implications for practice

Problem of retrieval

Searching for literature in a comprehensive care area such as palliative care is complex. The current study shows that large amounts of unique material are indexed on databases other than Medline meaning that in a field as wide-ranging and multidisciplinary as palliative care it would be wise to search multiple bibliographic sources.

Earlier research showed that up to 4% of general biomedical literature indexed on Medline could be relevant to palliative care. It also showed that retrieving this literature was difficult.[7] Effective searching requires sophisticated information competencies skills, adequate time and access to bibliographic sources.[19] The problems associated with clinicians being able to find needed information have already been highlighted in other studies.[20] Given these issues, it may be the time to consider whether expectations that individual clinicians should have these informatics competencies are realistic. Approaches that facilitate brokered access rather than rely on individual skills may prove to be not only more time effective but more efficient regarding the quality of the materials identified and retrieved. Strategies including the PubMed Topics Searches and CareSearch Review Collection within the CareSearch Web site,[21] the TRIP database[22] and the National Guideline Clearinghouse's Frequently Requested Searches[23] provide examples of how searching expertise and knowledge can be embedded into systems to facilitate access to published research literature.

Problem of knowledge management

Given that nearly 7000 palliative citations were identified for 2005 alone, keeping up to date with this literature would mean reading 19 articles a day. This is truly challenging, especially for those involved with palliative care on an intermittent basis. Although many of these articles may not be new research, a recent study found that one in every 14 palliative care articles indexed in OVID Medline was a clinical trial.[24] Ensuring the availability of this new evidence is fundamental to the development of evidence-based palliative care.

The multiplicity of database sources and the number of journals contributing to palliative care literature raises

Table 3 Journals with the largest number of palliative citations contributing 25% in one or more years (1995, 2000 and 2005)[a]

Journals in each of 3 years ($N = 16$)	Journals in two of the 3 years ($N = 10$)	Journals in only one of the 3 years ($N = 20$)
American Journal of Hospice and Palliative Care	*Caring*	*American Journal of Nursing*
Annals of Oncology	*Home Healthcare Nurse*	*Annals of Internal Medicine*
British Medical Journal	*International Journal of Palliative Nursing*	*Annals of Thoracic Surgery*
Cancer	*Journal of American Medical Association*	*British Journal of Surgery*
European Journal of Palliative Care	*Journal of Clinical Oncology*	*British Journal of Nursing*
Journal of Advanced Nursing	*Journal of Hospice and Palliative Nursing*[b]	*Der Chirug* (German)
Journal of American Geriatrics Society	*Journal of Pain and Palliative Pharmacotherapy/Hospice Journal*[c]	*Canadian Medical Association Journal*
Journal of Pain and Symptom Management	*Journal of Palliative Medicine*[d]	*European Journal of Cancer*
Journal of Palliative Care	*Lancet*	*European Journal of Cancer Care*
Nursing	*Medicina Paliativa* (Spain)	*Fanfare*
Nursing Standard		*Gan to Kagaku Ryoho* (Japanese)
Nursing Times		*Gastrointestinal Endoscopy*
Oncology Nursing Forum		*Hasting Center Report*
Palliative Medicine		*Home care and Hospice Update*
Seminars in Oncology		*International Journal of Radiation Oncology Biology Physics*
Supportive Care in Cancer		*MMW Fortschritte der Medizin* (German)
		Pain
		Palliative and Supportive Care[e]
		Psycho-Oncology
		Respiratory Care

[a] Where multiple journal titles shared the same number making up the 25%, all journal titles with that number of citations were included even if it increased the percentage marginally.
[b] First published in 1999.
[c] *Journal of Pain and Palliative Pharmacotherapy* is a continuation of the *Hospice Journal*.
[d] First published in 1998.
[e] First published in 2003.

issues about equitable access for practitioners in different settings. For palliative care (as for other multidisciplinary fields), the issue is how to develop a realistic framework for managing the burgeoning knowledge associated with practice in a way that enables access and supports use in the clinical setting. Again, resources such as the NHS specialist library on palliative care,[25] the BMJ's Clinical Evidence focus on Supportive and Palliative Care[26] and the CareSearch Clinical Practice pages and Finding Evidence [21] provide innovative approaches to the issue of knowledge management as they facilitate access to comprehensive resources on a clinical topic or care concept basis. In effect, they are mapping knowledge resources to the realities of clinical practice.

Problem of dissemination/knowledge translation

Ensuring that new knowledge reaches the multiplicity of health professionals involved in palliative care requires serious consideration. Publication of research evidence in a single journal is unlikely to lead to dissemination across the whole field.

The pattern of journal publication identified in this study may provide a guide to characterising potential users and sources for knowledge dissemination. Comprehensive dissemination strategies that address the implicit diversity of practitioners, sites of care and areas of clinical expertise and responsibility are needed. Also, given the variety of types of publications identified, researchers and policy makers need to consider the most appropriate formats for presentation and communication.

Limitations

The palliative search is likely to have systematically underestimated the number of palliative care citations given its high specificity and limited set of textwords. For example, other relevant terms such as bereavement or care of the dying may have identified further citations. Our chosen methodology did not allow the conduct of successive deduping exercises. Hence, we were not able to isolate unique material held only in each database. It is also possible that differences in processes for hand and automated deduping (both OVID and Endnote) activities may have marginally affected the data sets created. The publication history of each journal was not checked and there is the possibility of a slight overestimate of journal titles that may have changed their name or merged. Although the searches were not limited by language, the search terms were implicitly English and there was no intent to examine foreign language citations.

Conclusions

This study shows that there is a substantial and growing literature base for palliative care. Not only are Medline citations increasing, the unique amount of palliative care literature in EMBASE, CINAHL and PsycINFO deduped against Medline is also increasing. Further, the range of journals publishing palliative care material underlines the diversity of the profession's literature and evidence base highlighting the challenges the profession faces in identifying and retrieving this content. Knowledge management mechanisms that facilitate targeted and current access to the literature base will be important in supporting clinicians and services.

Ensuring that new knowledge reaches the range of palliative care clinicians (both specialists and generalists), policy makers and funders suggested by the number and diversity of journals publishing palliative care literature will require thoughtful and structured dissemination strategies. Publishing in a single journal is unlikely to result in the comprehensive spread of new information. These considerations are particularly significant given the role new knowledge and research can play in developing evidence-based practice within palliative care.

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