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doi:10.1080/07481187.2014.992498

Please cite this article as:

Tieman J, Hayman S, Hall C. Find me the evidence: Connecting the practitioner with the evidence on bereavement care, Death Studies 39(5) pp. 255-262

This is an Accepted Manuscript of an article published by Taylor & Francis in DEATH STUDIES on January 15 2015, available online: http:// www.tandfonline.com/10.1080/07481187.2014.992498

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FIND ME THE EVIDENCE: CONNECTING THE PRACTITIONER WITH THE EVIDENCE ON BEREAVEMENT CARE

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Acknowledgments: CareSearch is funded by the Australian Department of Health.

Keywords: Bereavement, Internet, Evidence-based practice, Palliative care, End of life

Grief and loss associated through the death of someone important to an individual is a challenging and defining experience. The effects of such a loss can be many and varied. Bereavement care seeks to alleviate and integrate the feelings and responses to loss to enable a bereaved person to continue to engage with living (Stroebe et al., 2001; Stroebe et al., 2008). In palliative care, where death is an anticipated event, there is both policy and service interest in the most appropriate nature and shape of bereavement care to support those who are affected by such loss (Agnew et al., 2010; Breen et al., 2014; Remedios et al., 2011). For example, in Australia, the National Palliative Strategy recommended the development of a national evidence based model for bereavement care (NPS 2010, p 8). Also, standards for bereavement support within palliative care services have been developed to offer structured guidance to assist with assessing and responding to those who are left bereaved (Hall et al., 2012).

Evidence from research studies, from epidemiology, from clinical activities, from practitioners, and from community perspectives can all inform how bereavement care is organised and delivered at a system, service and individual level (Arthur et al., 2011; Breen et al., 2014; Nagraj et al., 2001). Formal evidence from research studies can validate current practice or it can challenge existing models of care and highlight other options that could improve outcomes. Research can also stimulate new approaches and theories that can be explored and tested (Zhang et al., 2006). However, being able to use evidence assumes that the existing evidence is being found.

Bereavement care is a diffuse area. Practitioners in bereavement care come from diverse professions including nurses, doctors, social workers, psychologists and other allied health practitioners. They may work alone, in small teams or in large organisations. Bereavement care may be part of their responsibilities or it may be their sole speciality. Families and carers are also involved closely in caring for the bereaved. Practitioners can therefore have different knowledge needs and variable mechanisms to engage with the bereavement evidence and literature. Indeed, their working circumstances may affect their ability to access literature and knowledge resources in a timely and easy way (Chan & Tin, 2012; O'Connor et al., 2011). These factors can affect the individual's and the profession's ability to effectively access, review and use the evidence base for bereavement care.

The nature and structure of the bereavement knowledge base can also affect evidence retrieval. Concepts and terminology within the field are not always clearly delineated in the literature, making the evidence at times hard to identify and access. Kristjanson et al (2005) in their systematic review of complicated grief reported that "Considerable diversity in the use of adjectives to describe variations from normal grief and the conceptualisations of complicated grief were noted in the literature." (p 6.). Further, bereavement practitioners may have neither the time nor the skills and resources to spend crafting effective search strategies or may lack experience, skills or confidence in online searching. A mechanism that supports bereavement practitioners being able to find and retrieve relevant literature could therefore have value.

This study reports on the development and application of a Bereavement Search Filter with a known level of retrieval performance to support access to the underlying knowledge base for bereavement care.

Methods

The Bereavement Search Filter was developed using methodologies employed in previous studies to develop topic-based search filters including the Palliative Care Search Filter (Sladek et al., 2006), the Heart Failure Search Filter (Damarell et al., 2011) and the Residential Aged Care Search Filter (Dicker & Hayman, 2014). The methodology involved the following phases: (1) assessing options for and constructing a gold standard set; (2) term identification and testing; and (3) filter validation. This work was carried out in OvidSP Medline. OvidSP Medline offers particular functionalities that enable more controlled storage and testing of bibliometric data. A translation phase validated the use of the OvidSP Medline derived search filter for use within the PubMed environment. Finally, the search filter was deployed for use through the web. Figure 1 outlines the method.

The project activity was supported by an Expert Advisory Group¹ comprised of representatives from clinicians, policymakers and researchers. These experts provided advice throughout the project but specifically determined: the choice and composition of the gold standard reference set; the scope of the search filter (including important boundary concepts for the topic of bereavement); relevant terminology for testing; and specific topic searches to be built and published using the search filter. Further details on the phases of development are detailed below.

Gold Standard Set: To create an optimally sensitive search filter capable of retrieving relevant bereavement literature, a credible source and representative set of references are needed to test retrieval performance. This "gold standard" set of references must cover the range of topics agreed as implicit to the concept of bereavement. Options for a gold standard were identified by the project team and reviewed by the Expert Advisory Group to determine the option that most closely resembles the nature and characteristics of the literature as a whole. For this study, the gold standard comprised references of included studies from an agreed set of systematic reviews dealing with bereavement, grief and loss. References included in the Gold Standard needed to occur in the Medline database, to contain abstracts

¹ Members of the Expert Advisory Group were: Dr Lauren Breen, (ARC Discovery Early Career Researcher and Senior Lecturer, Undergraduate Psychology, School of Psychology and Speech Pathology, Curtin University); Mr Michael Bull (Senior Lecturer, School of Social Administration and Social Work, Flinders University); Dr Geoffrey Glassock (Counselling Psychologist); Mr Christopher Hall (Director, Australian Centre for Grief and Bereavement); Professor Liz Lobb (Professor of Palliative Care, Calvary Health Care Sydney and Cunningham Centre for Palliative Care; Adjunct Professor, School of Medicine, The University of Notre Dame, Sydney); Ms Dianne Moncrieff (Senior Social Worker, Ambulatory & Primary Health Care Service, Adelaide); Dr. Jon Stebbins (Bereavement Counsellor, Compassionate Friends, Victoria).

and to be in English. The set of 50 systematic reviews yielded a set of 828 references complying with these requirements. These were randomly divided into three reference subsets: term identification set, filter development set and filter validation set.

Filter Development: Frequency analysis of the titles and abstracts of the references in the Term Identification Set provided candidate terms for testing. This was supplemented by terms suggested or confirmed as relevant by the Expert Advisory Group. We tested terms singly and in combination for their recall performance in the Filter Development Set. The search strategy with the best performing combination of terms became the proposed OvidSP Medline search filter and its sensitivity was determined by calculating the number of retrieved items as a proportion of the number of relevant items in the Filter Validation Set. Sensitivity was tested in a different subset of references from those used to develop the filter, to prevent bias. Dual review of sets of items retrieved by the search filter in open Medline was completed by members of the Expert Advisory Group who determined the search filter's precision.

PubMed Translation: To ensure comprehensive capture of literature within PubMed, a search filter needs to search for citations held in the indexed subset of PubMed (records that are also indexed for Medline) and in the non-indexed subset of PubMed (records not contained in Medline). We translated the Bereavement Search Filter for PubMed using a validated experimental methodology (Damarell et al., 2013). We demonstrated equivalence in performance between the Bereavement Search Filter translated in syntax to search in the indexed component of PubMed and the Bereavement Search Filter in OvidSP Medline. The two strategies retrieved identical references from the Gold Standard Set in the two databases. To develop a search for use within the Non-Indexed subset, we determined potential losses in retrievals by using a search in the non-indexed set of the indexed search converted to textwords only. A post hoc relevance test, undertaken by pairs of external reviewers,

determined the precision of the non-indexed PubMed search filter. Combining the two PubMed searches with an OR operator forms the final and full PubMed version of the Bereavement Search Filter.

Web Deployment: To facilitate access to the search filter and to encourage its use, the search filter was created as a hyperlink within the CareSearch website that automates the loading of the filter into the PubMed database. Associated topic searches that combine the search filter with expert searches on topics of interest were also developed and deployed as hyperlinks. The Bereavement Search Filter project was undertaken in December, 2012 – November, 2013.

Results

An initial filter (OvidSP V1) was developed within OvidSP Medline. Although this search strategy retrieved 93% of items in the filter validation set, the assessed relevance by members of the Expert Advisory Group of the first 500 items retrieved when the search was run in open Medline was only 53%. Analysing the reasons provided for indicating that an item was not relevant suggested that the Expert Advisory Group believed that felt a more specific level of retrieval was required. A meeting of the Expert Advisory Group confirmed this preference. They agreed that a search filter specific to the palliative care context would have greater functional utility for the intended audience. Their clear clinical preference was for a search filter that would retrieve literature on bereavement resulting from death of a loved one, not for a more general set of literature on grief that may result from other causes (such as loss of a marriage, a job or a pet). We adjusted the draft filter to reflect this focus, chiefly by eliminating the MeSH term Grief from the search by not exploding Bereavement. Other changes included the removal of the MeSH term Widowhood and the addition of the text words Complicated grief and Prolonged grief, as relating specifically to grief in a bereavement context. Medline retrievals using the second version were reviewed by the

group. The second version (OvidSP V2) retrieved 81% in the filter validation set and 72% in post hoc relevance assessment (See Table 1).

A test of the retrieval performance of the OvidSP Medline search filter (OvidSP V2) translated for use in the indexed set of PubMed (PubMed Indexed Version) showed 100% equivalence, that is, they both retrieved the same 224/276 (81.2%) of the Gold Standard set of references (Filter Validation Set subset).

While converting the PubMed Indexed Version enables the search to be run in the nonindexed set, it may not maximise retrieval as there may be items that are identified only through the process of indexing. To test this, we ran the PubMed Indexed Version and a textword version of PubMed Indexed Version delimited to the period between 1/1/2010 and 31/12/2013. By combining the two sets of retrievals, we found that the textword variant retrieved 160 fewer articles. We called this "The Lost Set". In essence, without intervention, they would remain lost until indexing occurred. Given the non-indexed set includes the most recently published material awaiting indexing, increasing capture of these missing items is important. Frequency analysis of terms used in the Lost Set identified three additional terms and the need for adjustments to two existing terms to optimise the capacity to find items that would be missed by only textword conversion. The optimised Non-indexed PubMed Version retrieved 63/160 of the Lost Set. The remaining 97 records were analysed individually for terms that might be uniquely associated with bereavement and included in the filter as textwords. None were identified. Dual internal review of the first 100 retrievals indicated that 68% of items captured by the Non-indexed PubMed Search string were relevant to bereavement.

The full PubMed Version was formed by combining the two searches with 'OR' and limiting to their respective databases. The search filter is also limited to English only items.

A set of 21 areas that could inform aspects of bereavement care were identified by the Expert Advisory Group and from analysis of the key themes and topics of the included articles. Expert searches on these topics were created and combined with the Bereavement Search Filter. These were then converted to a URL that would load the search within PubMed with a choice for "all retrievals" or "free full text only". These hyperlink searches were then loaded to the CareSearch website as part of the Bereavement resources and are available for public use at http://www.caresearch.com.au/caresearch/tabid/2784/Default.aspx

AN ILLUSTRATIVE SEARCH

We present an illustration of the use of the Bereavement PubMed Searches on the CareSearch website, with an example of a search for evidence on the topic of *Complicated Grief*, of current interest in the bereavement field.

Jane, a bereavement counsellor who works in a small community-based team, is concerned to learn more about the nature of complicated grief and to find out some of the latest research on the topic. Jane has access to the internet but her organisation does not have a library or as far as she is aware any subscriptions to commercial databases. She wants to find some recent information quickly so that she can provide a summary to her team, to increase their general understanding of this topic.

She goes to the CareSearch website at <u>www.caresearch.com.au</u> (see Figure 2).

This website is free to use and does not require her to log on or remember any passwords. Jane clicks through to the Bereavement and Grief area of CareSearch following the path: *Clinical Evidence > Patient Care > Bereavement and Grief.* (See Figure 3.)

On this page she sees general information about Bereavement and Grief, in the palliative care context of CareSearch.

At the side is a link to Bereavement PubMed Searches and she clicks on this.

The message at the top of the page informs her that "The links on this page provide an easy, reliable way to find relevant bereavement literature in English. Each link runs an immediate and up-to-date search of PubMed." (See Figure 4.)

Jane sees that the list of topics includes **Complicated Grief**, and below that are two links, one to **Everything** and one to **Free full text only**. Jane wants to see full text articles immediately rather than be taken to a reference for something she may have difficulty obtaining; therefore she clicks on **Free full text only** below **Complicated Grief**. Immediately she is taken to the PubMed search results page for her search, through a link based on the validated Bereavement Search Filter, combined with terms selected to create an expert search on the topic of "complicated grief". Jane does not need herself to test all the different possible term combinations; this work has been done already and embedded in the link.

At the time of writing, the link to **Everything** returned 528 references. The link to **Free full text only** returned 109, the subset of the larger set of 528 which are immediately available in full through following the link to **Free PMC Article**. It is worth remembering that the number of retrievals will increase as new articles are added to the PubMed database.

The results page contains several articles that Jane immediately thinks will be useful. They are recent publications from 2013; her results come back with the most recent listed first with the first page containing references from 2012 - 2014, covering a range of areas within the topic of *Complicated Grief*. The search has found items where different terms ("complicated grief" and "prolonged grief") are used for the same concept.

Jane is interested in two articles, one on older adults and one on children. (See Figure 5).

For each of these, she clicks on the **Free PMC Article** link and is taken directly to the complete article.

Jane bookmarks the Bereavement PubMed Searches page at

http://www.caresearch.com.au/caresearch/tabid/2784/Default.aspx so that she can return directly to it.

Discussion

We have demonstrated that it is possible to create a validated subject-based search filter to retrieve literature relevant to bereavement. Access to research evidence, most commonly available as published journal articles, is important not only to inform bereavement care practices but to shape debate as to the role of research and evidence in bereavement care (Jordan, 2013). The Bereavement Search Filter is part of a knowledge infrastructure that can contribute to greater sharing of knowledge and evidence. Developed using a validated and replicable methodology and with a known effectiveness, the Bereavement Search Filter (in either the Medline or PubMed version), can reduce the challenges that health professionals face in searching and retrieving literature on bereavement. The rigorous methodology employed aims to ensure the Bereavement Search Filter is reliable in performance and optimised for purpose, that is, to support practitioners in quickly accessing literature relevant to bereavement.

The analysis undertaken in the course of this search filter development project confirmed the complexity of searching for literature in this field. The issues relating to terminology can clearly be seen in the relationship between grief and bereavement. While grief intuitively may seem to be a more encompassing concept of loss than bereavement alone, indeed grief is the more encompassing MeSH term described as referring to "the whole process of grieving and mourning and is associated with a deep sense of loss and sadness". Indeed the MeSH subject heading Bereavement includes the term Grief as a narrower term. Entering Bereavement as a MeSH term will therefore automatically "explode" and trigger a search for the term Grief as well. To ensure a more precise set of Bereavement only retrievals, an individual would need to be familiar with the MeSH construction and the syntax required to adjust the search; skills many bereavement care providers may not have. The processes associated with developing the Bereavement Search Filter highlight the importance of the clinical and professional input in creating functionally useful resources. The post hoc relevance testing of the first draft search strategy by pairs of reviewers from the Expert Advisory Group identified an inappropriate level of irrelevant retrievals that would have diminished the value of the search filter in its practical applications. The value of a search filter to the intended user is a balance between what it finds and what it excludes, that is, maximising relevant retrievals and reducing irrelevant retrievals.

Given that some grief counsellors may require a broader literature to support their practice, the work undertaken in the development of the Bereavement search filter will underpin the future development of a companion search filter which aims to retrieve the literature across bereavement, grief and loss more generally.

Current relevant evidence can be valuable for informing clinical practice, as well as for service and policy decision-making. By creating the searches as hyperlinks, practitioners can immediately gain access to literature without the necessity of re-entering the search to the Medline database. Through the provision of these searches on the CareSearch website, bereavement counsellors have free and public access to this searching resource. Web-based searching enables users to search for literature, regardless of location or time. As PubMed is an open access citation database, users do not have to have registration rights or enter a password. The evidence retrieved is continuously updated as new literature is published and is drawn from journals published across the world. A free full text limit means that practitioners can limit retrievals to articles they can read in full without charge rather than

articles they will need to purchase or order. This customisation creates additional value for busy clinicians.

The specific searches on bereavement-related topics include a range of contemporary issues such as Complicated Grief, Memorial and Rituals, and Quality Improvement. The user can also create a specific topic search using the Bereavement Search Filter as a base. Instructions are included on the website. For example, it is possible to run the PubMed Bereavement Search Filter and then combine it with a topic search of one's own, such as cancer, and retrieve a subset of the Bereavement Filter Search results, relevant to one's own topic of interest. These searching resources create further value for the individual user and for the profession and provide a mechanism that supports evidence use and knowledge translation.

CONCLUSION

Access to the literature of evidence about best practice in bereavement care will lead to better outcomes for those who are suffering the loss of a loved one and are in need of support. Much of this literature is found in journals and indexed in the PubMed database, but it is not always easy for clinicians in the bereavement field to search and retrieve it effectively. The Bereavement Search Filter is a new search filter that has been developed and validated to target literature on bereavement care. It is a transparent, reproducible, fixed search strategy, providing continuous access to current information worldwide. It enables links on the CareSearch website to take the user directly into the PubMed database search results. It is free, simple and quick to use and embeds technical search effectiveness to link bereavement practitioners to clinical evidence. Our ultimate aim is to encourage knowledge use that will lead to better patient care through the automated retrieval of evidence.

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Figure 1: Phases of development of the Bereavement Search Filter



Figure 2: The CareSearch website front page

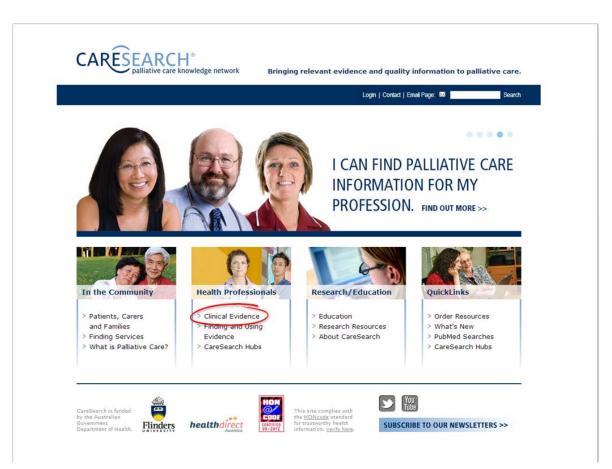


Figure 3: The CareSearch website Bereavement and Grief page

		CARESEARCH [®] palliative care knowledge network			
Main Menu	Clinical Evidence	Login Feedback Email Page: 🖾 Font size: 🔺	A A Search		
What is Palliative Care?	Advance Care Planning	You are here: Clinical Evidence » Patient Management » Bereavement and Grief			
Patients, Carers and Families	Patient Management				
Finding Services	Ŭ	Bereavement and Grief			
Clinical Evidence	> Appetite Problems	Overview			
Finding and Using Evidence	> Anxiety	Bereavement refers to the experience surrounding the death of	PubMed Searches		
Education	> Bereavement and Grief	a person with whom there has been an enduring	Bereavement		
Research Resources	- Complicated Grief	relationship. Bereavement is the "entire experience of family members and friends in the anticipation, death and subsequent	Free full text only <u>Strongest evidence</u> Everything		
CareSearch Hubs	 Bereavement PubMed Searches Create Your Own Bereavement PubMed Search Breathing 	adjustment to living following the death of a loved one." [1] It	All Citations		
About CareSearch		therefore includes psychological expressions and adaptations of	Strongest evidence		
Contact CareSearch		families and communities in terms of relationships and future expectations.	Everything Last 3 months		
Home		Grief is how bereavement affects us personally and is a	About these searches		
		universal human experience. Grief, especially in the early stages, often causes disruption and disturbance of everyday	About these searches		
	> Complementary Therapies	life. However, grief can be expressed by people very differently. Some people do not experience an intense reaction.	Bereavement Grief and Loss		
	> Constipation	Most people experience fluctuating reactions for a period of time while others can develop a <u>complicated grief reaction</u> . [2] Grief is a "set of cognitive, emotional and social difficulties that follow the death of a loved one. Individuals vary			
	> Delirium				
	> Depression	enormously in the type of grief they experience, its intensity, its duration and their way of expressing it." [1] Culture can play a major role in the expression of grief. [3]			

Figure 4: The CareSearch Bereavement PubMed Searches page.

dvance Care Planning	Searches	Patient Management » Bereavem	ent and Grief » Bereavement PubMe		
atient Management					
Appetite Problems	Bereavement PubMed Searches				
Anxiety	The links on this page provide an easy, reliable way to find relevant bereavement literature in English. Each link runs an immediate and up-to-date search of PubMed.				
Bereavement and Grief	CareSearch search filters				
Complicated Grief	These searches use the Bereavement Search Filter developed by CareSearch. It retrieves all				
Bereavement PubMed Searches	English language articles of relevance to bereavement within PubMed. Bereavement specific issue searches				
0					
Create Your Own Bereavement PubMed	Service Delivery Issues	Specific groups	Therapies		
Search Breathing	Assessment and Prediction	Aboriginal and Torres Strait Islander People	Cognitive Behavioural Therapy		
Li chan n'g	Everything	Everything	Everything		
Complementary Therapies	Free full text only	Free full text only	Free full text only		
Constipation	Ethics	Children and Adolescents	Community Support		
Delirium	Everything	Everything	Everything		
Delinum	Free full text only	Free full text only	Free full text only		
Depression	Memorial and Rituals	Complicated Grief	Grief Counselling		
End-of-Life Care	Everything	Everything	Everything		
	Free full text only	Free full text only	Free full text only		
Fatigue					
Nausea	Models of Service Delivery	GLBTI	Medication		
nausea	Everything	Everything	Everything		
Pain	Free full text only	Free full text only	Free full text only		
Sleeping Problems	Quality Improvement	Multicultural	Patient Education and Grief Information		
Social Support	Everything	Everything	Everything		
C. Anima	Free full text only	Free full text only	Free full text only		
Suffering	Self Care	People with a Disability	Spirituality		
mily and Carer Evidence	Everything	Everything	Everything		
ervice Delivery Evidence	Free full text only	Free full text only	Free full text only		

Figure 5: Selected results from the Complicated Grief CareSearch Bereavement

PubMed Search

- Outcomes of bereavement care among widowed older adults with complicated grief and
- depression.
 Ghesquiere A, Shear MK, Duan N. J Prim Care Community Health. 2013 Oct;4(4):256-64. doi: 10.1177/2150131913481231. Epub 2013 Mar 11. PMID: 23799667 [PubMed - in process] Free PMC Article Related citations
- Identifying prolonged grief reactions in children: dimensional and diagnostic approaches.
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Search Version	Search Strategy	Retrieval performance	Relevance assessment
Search Development in Indexed Set (Medline)		Filter Validation Set	Open Medline
OvidSP V1	exp bereavement/ or bereav*.ti,ab. or grief.ti,ab. or widowhood/ or grieving.ti,ab. or continuing bond*.ti,ab. or spousal loss.ti,ab.		
OvidSP V2	bereavement/ or bereav*.ti. or grief.ti. or grieving.ti. or continuing bond*.ti,ab. or spousal loss.ti,ab. or complicated grief.ti,ab or prolonged grief.ti,ab	224/276 (81.2%)	181/250 (72.4%)
PubMed Indexed Version	"bereavement"[mh:noexp] OR bereav*[ti] OR grief[ti] OR grieving[ti] OR continuing bond*[tiab] OR spousal loss[tiab] OR complicated grief[tiab] or prolonged grief[tiab]	224/276 (81.2%)	NA
Search Development in Non-indexed Set (PubMed)		"Lost Set"	Open PubMed – non- indexed
PubMed Non- indexed Version	bereav*[tiab] OR grief[tiab] OR widow*[tiab] OR grieving[tiab] OR grieve*[tiab] OR loss of a child[tiab] OR funeral*[tiab] OR parental death[tiab] OR death of a parent[tiab] OR continuing bond*[tiab] OR spousal loss[tiab]	63/160 (39.8%)	68/100 (68%)
Final Version for U Full PubMed Version	Jse In PubMed (Indexed and Non-indexed Sets) ("bereavement"[mh:noexp] OR bereav*[ti] OR grief[ti] OR grieving[ti] OR continuing bond*[tiab] OR spousal loss[tiab] OR complicated grief[tiab] or prolonged grief[tiab] AND medline[sb]) OR (bereav*[tiab] OR grief[tiab] OR widow*[ti] OR grieving[tiab] OR grieve*[tiab] OR loss of a child[tiab] OR death of a parent[tiab] OR continuing bond*[tiab] OR spousal loss[tiab] NOT medline[sb])	NA	NA

TABLE 1Performance of search filter versions