

Reporting of 'Death and Bereavement Care': A Systematic Review and Quantitative Analysis of Research Publications in Palliative Care Journals

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Abstract

Context: The most common concern among terminally ill patients in palliative care is death, which is often perceived as a psychosocial stigma. The knowledge, attitudes, beliefs and experiences regarding death influence both the delivery of palliative care and its outcomes.

Aims: This study aimed to perform a quantitative analysis of research publications in palliative care journals for articles on Death and bereavement care (DBC).

Settings and Design: Systematic review of palliative care journals.

Methods and Material: Twelve palliative care journals were searched for articles related to 'death' in title of the articles published in 2009 and 2010. The reporting rates of all journals were compared. The selected articles were categorized into practice, education, research and administration, and subsequently grouped into original and review articles. The original articles were sub-grouped into qualitative and quantitative studies, and the review articles were grouped into narrative and systematic reviews. Each subgroup of original articles category was further classified according to study designs.

Statistical analysis used: Descriptive analysis using frequencies and percentiles was done using SPSS for Windows version 11.5.

Results: The overall reporting rate among all journals was 5.27% (96/1821), and *Palliat Support Care* had highest reporting rate of 14.4% (17/118), followed by *BMC Palliat Care* with 9.3% (4/43), and *Palliat Med* with 7.4% (16/216).

Conclusions: The overall reporting rate for DBC articles in palliative care journals was very low and there were very few randomized clinical trials and systematic reviews found. The study findings indicate a lack of adequate evidence base for DBC.

Keywords: Evidence-based palliative care; Research; Journal reporting; Publication trend; Death; Bereavement.

"The question is not how, when or where we will die, but how, when and where we will live until death."

Introduction

The most common concern for terminally ill patients undergoing palliative care is death.

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[1] The goals of palliative care in the treatment of terminally ill patients are to improve their symptom control,[2] level of functioning[3] and quality of life (QoL).[4] Death is often regarded as a complex psychosocial stigma which individuals at end-of-life often avoid discussions or interactions about.[5] Though death of an individual is an ultimate reality,[6] the reactions of the patient themselves (on impending death), or the caregivers and health care professionals (before and after a patient's death) need not be similar in all situations[7] and it should be understood that death is not a failure in palliative care but a reality.[8] These differences may not only be

attributed to the medical diagnoses, the symptom experience and treatment side-effects but also mostly to the socio-cultural[9] and demographic influences.[10] Thus it is the responsibility for a palliative care team to make dying as a living process for both patients and staff.[11] The caring process extends from a continuum of supportive care to end-of-life care and then on to post-bereavement care and is an essential component in a palliative health care model.[12,13]

Death does involve moral,[14-17] legal,[15,16,18] ethical,[19,20] spiritual[15,21] and practical[22,23] issues both for the family and the health care team, and thus it is imperative that information and communication about death should be encouraged in routine clinical practice.[24] Issues related to impending death may be on 'good death',[25] causation,[26] 'place of death'[27,28] and psychosocial issues (anxiety,[29] denial[30,31]). Right from referral until death, the palliative care outcomes measured should directly reflect the symptom pathways that patient's experience.[32]

Despite the growing emphasis on Death and bereavement care (DBC) in clinical palliative care practice and in palliative care education,[33-35] death is often stigmatized, and management is frequently suboptimal. The attitudes towards death, both of patients[36] and health care professionals[37,38] determine the time-course of a healthy[39] and joyful[40] death, which is the ultimate goal of palliative care. The current evidence era and the ensuing evidence-based practice warranted application of current research evidence into clinical decision making to facilitate evidence-based palliative care (EBPC).[41] Thus an analysis of research evidence could not be based upon anecdotal findings and thus there is a need to evaluate the reporting of research on DBC in palliative care journals. Previously published studies on analysis of palliative care journals were on reporting of moral problems (ethical issues),[42] euthanasia,[43] chaplains and community-based clergy,[44,45] religion and spirituality,[45-47] cancer pain,[48] pediatric palliative care,[49] quality of life,[50] and cancer-related fatigue.[51] The objective of this

paper was to perform a quantitative analysis of research articles on Death and bereavement care (DBC), published in palliative care journals over the past two years.

Materials and Methods

Search strategy and criteria

Journals indexed in MEDLINE with name 'palliative' were included and searched for English papers with 'death OR die OR dying OR dead OR bereaved OR bereavement' in title of the papers in 2009 and 2010.

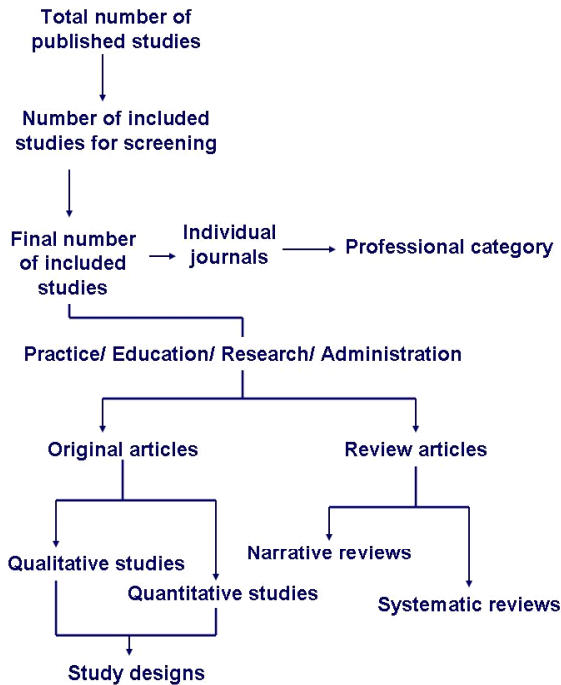
Data synthesis

The total number of articles in all the selected journals was taken as N. The number of included DBC articles (N_1) based on search criteria were compared with total number of articles (N) to obtain reporting rates ($N_1/N\%$) for each journal. Such an estimate provided reporting rate (RR) for DBC. The journals were categorized broadly into multidisciplinary, medical, nursing and other (social work) categories of palliative care journals. The included studies were grouped under four aspects-practice, education, research and administration and then categorized into original articles and review articles under each of the four aspects. The original articles were then again grouped into qualitative and quantitative studies. The review articles were grouped into narrative and systematic reviews. The qualitative and quantitative studies were then sub-grouped based upon study designs. Number of articles reported in each of the final subgroups was computed. The procedure of data synthesis is explained in the schematic flowchart (Figure 1).

Data analysis

Descriptive analysis using frequencies for number of studies with respective percentiles was used for reporting characteristics and was done using 95% confidence interval by SPSS for Windows version 11.5 (SPSS Inc, IL).

Figure 1: Schematic flowchart for data synthesis used in this study



Comparison between journals and article-categories were done visually.

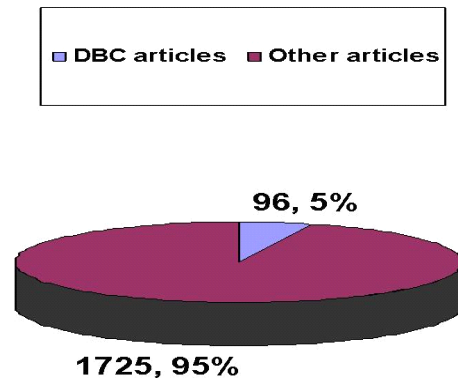
Results

Overall journals' characteristics

The study included twelve palliative care journals with a total number of 1821 articles and 96 included articles which met the inclusion criteria. The overall two-year reporting rate for articles on DBC is 5.27% (Figure 2). AJHPC-Am J Hosp Palliat Care; BMCPC-BMC Palliat Care; COSPC-Curr Opin Support Palliat Care; IJPC-Indian J Palliat Care; IJPN-Int J Palliat Nurs; JHPN-J Hosp Palliat Nurs; JPPCP-J Pain Palliat Care Pharmacother; JPC-J Palliat Care; JPM-J Palliat Med; JSWELPC- J Soc Work End Life Palliat Care; PM- Palliat Med; and, PSC-Palliat Support Care.

Individually AJHPC had 16 articles, BMCPC had four articles, COSPC had one article, IJPC had two articles, IJPN had 12 articles, JHPN had zero articles, JPPCP had zero articles, JPC had six articles, JPM had 21 articles,[33-44] JSWELPC had one article, PSC

Figure 2: Overall prevalence of reporting 'death and bereavement care' (DBC) in all the palliative care journals



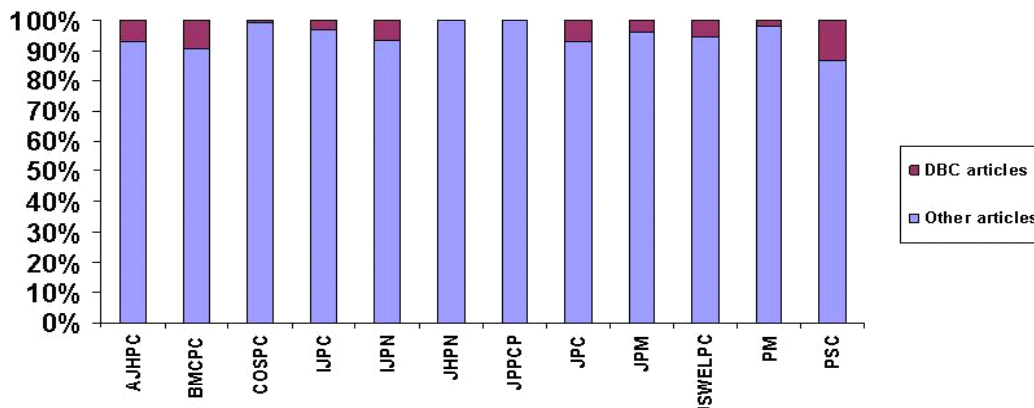
had 17 articles and PM had 16 articles on DBC. Also refer Table 1 for respective reporting rates and Figure 3 for comparison of number of DBC articles and 'other' articles between the journals. PSC had highest reporting rate of 14.4% (17/118), followed by BMCPC with 9.3% (4/43), and PM with 7.4% (16/216).

Of the selected journals, seven were multidisciplinary (AJHPC, BMCPC, COSPC, IJPC, JPC, JPPCP, PSC) with a reporting rate of 5.15% (46/892), two were medical (JPM, PM) with a reporting rate of 5.17% (37/715), two were nursing (IJPN, JHPN) with a reporting rate of 6.15% (12/195), and one was other (social work-JSWELPC) with a reporting rate of 5.26% (1/19). (Figure 4).

DBC studies on four aspects of practice, education, research and administration:

Of the 96 included articles, 79 articles were on practice,[52,54-62,64,66-70,72,74-7,79-92,94-7,99-104,106,107,114,115,117-22,124-47]eight articles were on education,[53,73,78,93,105,108,110,123] there were no articles on research and nine articles on administration. [63,65,71,98,109,111-3,116]

Of the 79 articles on DBC practice, there were 65 original articles[55,56,58,60-2,64,66,67,69,70,74-7,79-92,94-7,99-104,106,107,114,117-20,122,124,126-34,136,137,141-3,145-7] and 14 review articles.[52,54,57,59,68,72,115,121,125,135,138-40,144] Of the 65 original articles, 51 studies used qualitative methods[55,56,58,60-62,64,66,

Figure 3: Comparison of reporting rates of 'death and bereavement care' (DBC) articles between palliative care journals

(AJHPC- Am J Hosp Palliat Care; BMCPC- BMC Palliat Care; COSPC- Curr Opin Support Palliat Care; IJPC- Indian J Palliat Care; IJPN- Int J Palliat Nurs; JHPN- Journal of Hospice and Palliative Nursing; JPPCP- J Pain Palliat Care Pharmacother; JPC- J Palliat Care; JPM- J Palliat Med; JSWELPC- J Soc Work End Life Palliat Care; PM- Palliat Med; PSC- Palliat Support Care).

Table 1: Comparison of reporting rates of palliative care journals on 'death and bereavement care' (DBC) articles

	Total number of articles (2009-2010) N	Number of articles on DBC N ₁	Reporting rate (N _R) N ₁ /N%
<i>Am J Hosp Palliat Care</i> ^a	226	16	7.07%
<i>BMC Palliat Care</i> ^a	43	4	9.3%
<i>Curr Opin Support Palliat Care</i> ^a	99	1	1.01%
<i>Indian J Palliat Care</i> ^a	59	2	3.38%
<i>Int J Palliat Nurs</i> ^c	187	12	6.41%
<i>J Hosp Palliat Nurs</i> ^c	8	0	0
<i>J Pain Palliat Care Pharmacother</i> ^b	261	0	0
<i>J Palliat Care</i> ^a	86	6	6.97%
<i>J Palliat Med</i> ^b	499	21	4.20%
<i>J Soc Work End Life Palliat Care</i> ^d	19	1	5.26%
<i>Palliat Support Care</i> ^a	118	17	14.40%
<i>Palliat Med</i> ^b	216	16	7.40%
Total number of articles, N or overall reporting rate, %	1821	96	5.27%

a- multi-disciplinary journals; b- medical journals; c- nursing journals; d- other (social work)

67,69,74-7,80-92,94,97,99,101,102,114,117,120,122,124,126-33,136,137,141,143,145,147] and 14 studies used quantitative methods.[70,79,95,96,100,103,104,106,107,118,119,134,142,146] Among the 51 qualitative studies, there were no randomized clinical trials, two non-randomized clinical trials,[67,126] eight cohort studies,[56,58,62,69,88,101,130,132] 35 cross-sectional studies[55,60,64,66,74-7,80-7,89-

92,94,102,114,117,122,124,127,128,131,133,137,141,143,145,147] and six case reports.[61,97,99,120,129,136] Among the 14 quantitative studies, there was one randomized clinical trial,[142] seven cohort studies,[70,79,100,106,107,118,134] one case-series,[104] four cross-sectional studies[95,96,103,146] and one case report. Refer to Table 2 for respective comparisons among studies on practice.

Figure 4: Comparison of reporting rates between multidisciplinary, medical, nursing and other palliative care journals

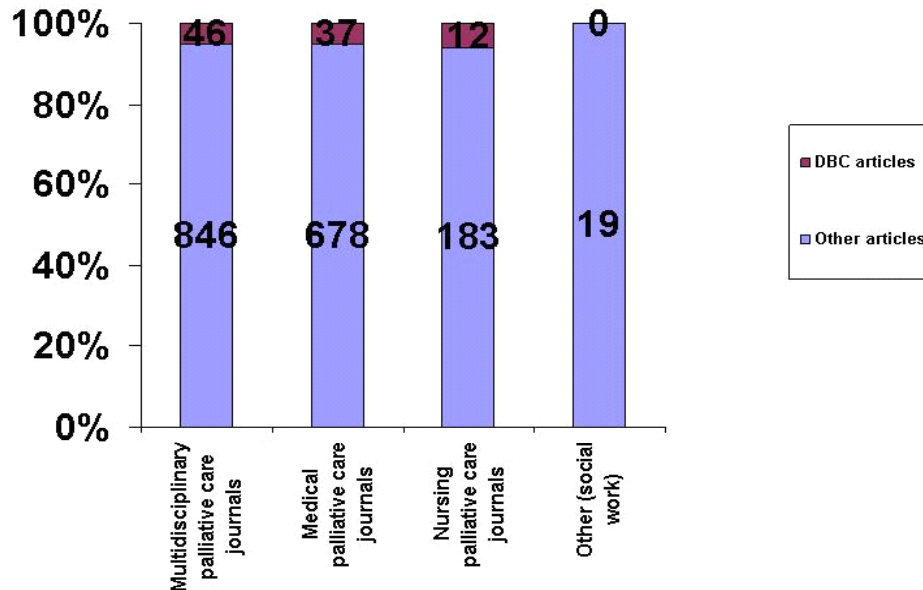


Table 2: Characteristics of practice-related articles on 'death and bereavement care' (DBC) in terms of their type of article, method of research and study design

Total number of articles N ₂	Type of articles	Number of articles N ₃ (%= N ₃ /N ₂)	Types of research methods	Number of articles N ₄ (%= N ₄ /N ₂)	Study designs	Number of articles N ₅ (%= N ₅ /N ₂)
79	Original articles	65 (82.27%)	Quantitative studies	14 (17.72%)	Randomized clinical trial	1 (1.26%)
					Non-randomized clinical trial	0 (0)
					Cohort study	7 (8.86%)
					Case-series	1 (1.26%)
					Cross-sectional study	4 (5.06%)
			Case report		1 (1.26%)	
			Qualitative studies		Randomized clinical trial	0
					Non-randomized clinical trial	2 (2.53%)
					Cohort study	8 (10.12%)
					Case control study	0
	Cross-sectional study	35 (44.30%)				
	Case report	6 (7.59%)				
Review articles	14 (17.72%)	Narrative reviews	51 (64.55%)	9 (11.39%)		
				Systematic reviews	5 (6.32%)	

Table 3: Characteristics of administration-related articles on 'death and bereavement care' (DBC) in terms of their type of article, method of research and study design

Total number of articles N ₂	Type of articles	Number of articles N ₃ (% = N ₃ /N ₂)	Types of research methods	Number of articles N ₄ (% = N ₄ /N ₂)	Study designs	Number of articles N ₅ (% = N ₅ /N ₂)
9	Original articles	9 (100%)	Qualitative studies	6 (66.67%)	Randomized clinical trial	0
					Non-randomized clinical trial	0
					Cohort study	4 (44.44%)
					Case control study	0
					Cross-sectional study	2 (22.22%)
					Case report	0
			Quantitative studies	3 (33.33%)	Randomized clinical trial	0 (7.14%)
					Non-randomized clinical trial	0
					Cohort study	3 (33.33%)
	Case control study	0				
	Cross-sectional study	0				
	Case report	0				
Review articles	0	Narrative reviews	NA			
		Systematic reviews	NA			

Of the eight articles on DBC education, there were seven original articles[53,73,78,93,108,110,123] and one review article.[105] Among the seven original articles, all seven studies used qualitative methods[53,73,78,93,108,110,123] and there was one non-randomized clinical trial,[123] one cohort study[108] and five cross-sectional studies[53,73,78,93,110] in them.

There were no articles found that focused on the aspect of research on DBC.

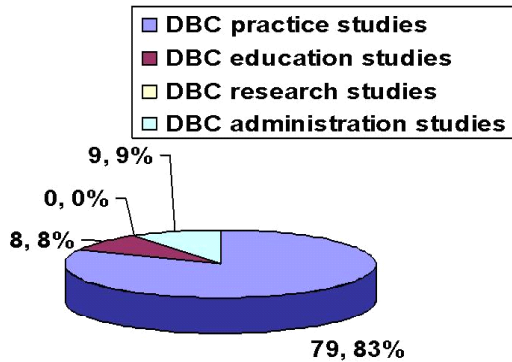
Of the nine articles on DBC administration, all were original articles[63,65,71,98,109,111-3,116] which comprised of six qualitative studies[63,65,98,109,113,116] and three quantitative studies.[71,111,112] There were four cohort studies[63,98,113,116] and two cross-sectional studies[65,109] amongst the six

qualitative studies. All the three quantitative studies were cohort studies.[71,111,112] Refer to Table 3 for analysis of studies on administration.

Relative prevalence of articles on practice, education, research and administration is shown in Figure 5 and their comparison for original and review articles on DBC are provided in Figure 6.

Comparison of original articles among aspects for qualitative and quantitative study methods is shown in Figure 7 and comparison between the three aspects (since there were no article on DBC research) of original articles for their study designs is given in Figure 8, Figure 9 and Figure 10 respectively.

Figure 5: Prevalence of articles on 'death and bereavement care' (DBC) for studies on practice, education, research and administration



Discussion

This study is essentially the first of its kind of a review of palliative care journals utilizing a systematic approach to quantitatively identify reporting characteristics of articles on death and bereavement care (DBC). This study included 12 palliative care journals. The previous authors- Hermsen and ten Have reviewed 12 palliative care journals from 1984 to 1999,[42,43] found reporting rate of 12% for ethical issues (458 articles) and euthanasia rate was unreported (75 articles). Hermsen

Figure 6: Comparison of two categories of articles (original, review articles) among the three 'death and bereavement care' (DBC) article aspects (practice, research and administration)

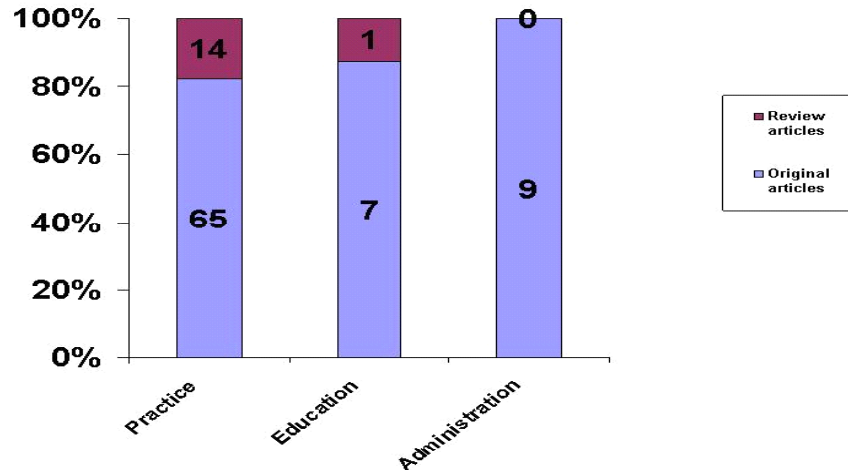
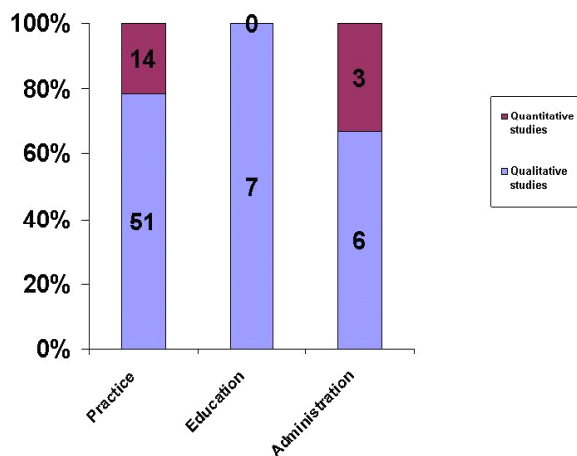
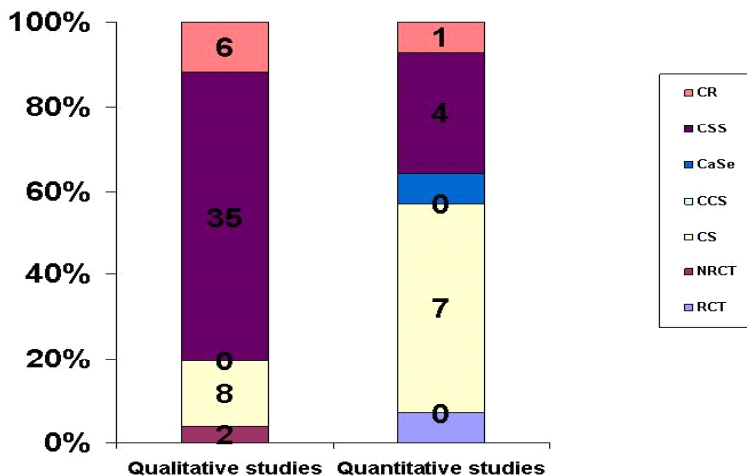


Figure 7: Comparison of two methods of original articles (qualitative, quantitative) among the three 'death and bereavement care' (DBC) article aspects (practice, research and administration)



and ten Have[45] reviewed 12 journals from 1984-2002 and found a reporting rate of 2% for 80 articles on spirituality, pastoral care and religion. Flanelly *et al*[44] reviewed three palliative care journals from 1990-1999 and they found a reporting rate of 5.6% (47/838) for articles on role of chaplains and clergy. Kumar found a two-year reporting rate of 5.6% for cancer pain articles[48] in 19 palliative care journals and five-year reporting rate of 2.66% for pediatric palliative care[49] articles in 12 palliative care journals, five-year reporting rate of 1.96% for articles on quality-of-life[50] in 12 palliative care journals and a five-year reporting rate of cancer-related fatigue[51] in 12 palliative care journals to be 1.04%. The reason why this study found a

Figure 8: Comparison between qualitative and quantitative types of articles on practice of 'death and bereavement care' (DBC) for reporting rates of different study designs

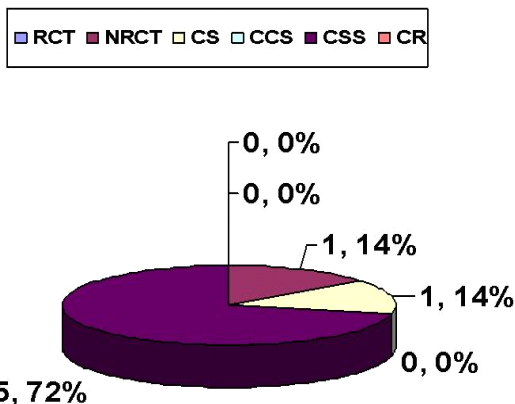


(RCT- randomized clinical trial; NRCT- non-randomized clinical trial; CS- cohort study; CCS- case-control study; CaSe- case series; CSS- cross-sectional study; CR- case report)

comparatively better reporting rate in lesser number of years of publication (compared to the reporting rates of pediatric palliative care, quality of life and cancer-related fatigue) could only be due to the greater emphasis given towards DBC in the palliative care journals in the recent years. This study included journals as they are indexed in MEDLINE since it is the common database for evidence search and the last two years of analysis provided current information on reporting rates.

The study found some interesting

Figure 9: Prevalence of reporting qualitative studies on education of 'death and bereavement care' (DBC) for different study designs

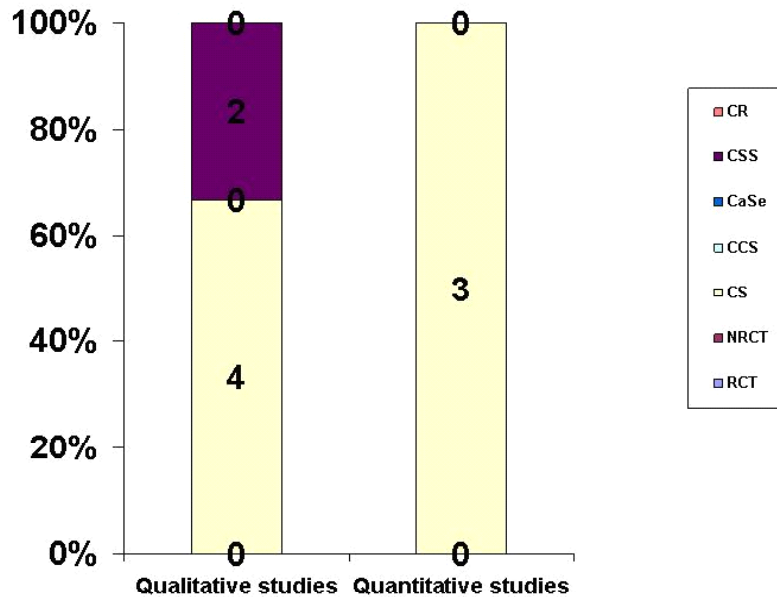


(RCT- randomized clinical trial; NRCT- non-randomized clinical trial; CS- cohort study; CCS- case-control study; CaSe- case series; CSS- cross-sectional study; CR- case report)

observations-some expected, some rather unexpected. As expected, clinical focus on DBC was evident when a greater proportion of practice-related articles were found among the four aspects considered. Another expected finding was a lack of observed difference in reporting between professional categories of palliative care journals. The few unexpected observations include: absence of articles focusing exclusively on research in DBC, lack of quantitative studies on DBC education and very few randomized clinical trials (either qualitative or quantitative) and/or systematic reviews were found. The insufficient number of systematic reviews and randomized clinical trials virtually undermines the current EBPC since they are ranked the highest in hierarchy among the levels of evidence.

Healthcare professionals need to be aware of the relatively better reporting of DBC articles in palliative care journal literature and should shoulder responsibility to foster better number of reporting high quality research on DBC for evidence-based palliative care (EBPC). In future, similar reviews could be performed with quality appraisal and identify the quality of reporting DBC articles. Also, reviews from other related journals like *Death Studies*, *Death Education* and/or general medical journals may yield different results. Comparison of reporting characteristics between journals

Figure 10: Comparison between qualitative and quantitative types of articles on administration of 'death and bereavement care' (DBC) for reporting rates of different study designs



(RCT- randomized clinical trial; NRCT- non-randomized clinical trial; CS- cohort study; CCS- case-control study; CaSe- case series; CSS- cross-sectional study; CR- case report)

based on their specialty would direct clinicians to find research appropriate to answer their relevant clinical questions during EBPC.

Conclusion

The overall 2-year prevalence in reporting of articles on death and bereavement care (DBC) was low, only 5.27% among the 12 palliative care journals reviewed in this study. There were no articles found on DBC research and there were very few randomized clinical trials and systematic reviews found. These review findings indicate a lack of adequate evidence base for DBC and further high quality clinical trials are required to base effective clinical decisions on DBC for a better palliative care clinical practice.

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