

Original Article

Reporting of Pediatric Palliative Care: A Systematic Review and Quantitative Analysis of Research Publications in Palliative Care Journals

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ABSTRACT

Context: Pediatric palliative care clinical practice depends upon an evidence-based decision-making process which in turn is based upon current research evidence.

Aims: This study aimed to perform a quantitative analysis of research publications in palliative care journals for reporting characteristics of articles on pediatric palliative care.

Settings and Design: This was a systematic review of palliative care journals.

Materials and Methods: Twelve palliative care journals were searched for articles with “paediatric” or “children” in titles of the articles published from 2006 to 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 subgrouped 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 2.66% (97/3634), and *Journal of Hospice and Palliative Nursing* (JHPN) had the highest reporting rate of 12.5% (1/8), followed by *Journal of Social Work in End-of-Life and Palliative Care* (JSWELPC) with a rate of 7.5% (5/66), and *Journal of Palliative Care* (JPC) with a rate of 5.33% (11/206).

Conclusions: The overall reporting rate for pediatric palliative care articles in palliative care journals was very low and there were no randomized clinical trials and systematic reviews found. The study findings indicate a lack of adequate evidence base for pediatric palliative care.

Key words: Evidence-based pediatric palliative care, Journal reporting, Publication trend, Research

INTRODUCTION

The World Health Organization defines palliative care for children as “the active total care of the child’s body, mind and spirit...also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment

directed at the disease.”^[1] Pediatric palliative care is concerned with the medical, psychosocial, spiritual, and economic needs of patients and their families, providing complex patient care solutions involving all aspects of the healthcare system, from hospital to hospice, to community, and to home, and it involves an interdisciplinary team of caregivers.^[2]

Four different categories of childhood diseases have been identified by the Association for Children with Life-Threatening or Terminal Conditions (ACLTC) and the Royal College of Pediatrics and Child Health (RCPCH): (1) life-threatening conditions for which curative treatment may be feasible but can fail, where

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palliative care is provided together with attempts at curative treatment (cancer, irreversible organ failure); (2) diseases which are life-threatening at an early age, where appropriate treatment may prolong life and provide an adequate quality of life (cystic fibrosis); (3) progressive conditions without curative treatment options, where treatment is exclusively palliative (some chromosomal diseases, muscular dystrophy, rare metabolic diseases); and (4) nonprogressive, irreversible conditions, with complex healthcare needs, that give rise to many complications and premature death (spinal muscular atrophy, severe cerebral palsy, brain or spinal cord injuries due to trauma or infection).^[3,4] The predominant primary clinical conditions encountered in a pediatric palliative care setting were genetic/congenital (40.8%), neuromuscular (39.2%), cancer (19.8%), respiratory (12.8%), and gastrointestinal (10.7%).^[5]

Improving the care provided to these children is likely to have the largest impact on quality of life and longevity.^[6] The low prevalence of most severe pediatric diseases also makes it difficult to evaluate the effectiveness of new treatment modalities; multicenter trials or long enrollment periods are usually required to obtain a large enough patient sample to conduct the necessary randomized controlled trials or cohort studies.^[6] Another challenge encountered when measuring quality of care for children is that, in most cases, they depend on adults to both obtain care and report on the outcomes of that care.^[6,7]

Palliative care is a multidisciplinary profession and is being recognized as a separate field on its own. Evidence-based palliative care (EBPC) involved integrating effective research findings with clinical expertise and patient preferences toward better individualized provision of palliative care for patients.^[8] One of the main causes for the lack of quality in provided care for the pediatric population in an era of evidence-informed/ evidence-based practice is the lack of adequate research evidence^[9] and this may be due to the following possible reasons: lesser studies being conducted on pediatric palliative care, publication of lesser number of studies, ethical issues^[10] and reporting characteristics of such studies. Despite an increasing global need for high-quality pediatric palliative care,^[11] 65.6% of countries had no known activities reported on pediatric palliative care around the world.^[12] Evidence-based pediatric palliative care (EBPPC) demands palliative healthcare professionals to have updated knowledge of current research evidence (commonly obtained from palliative care journals) for effective translation into palliative care for the pediatric population.

Previously published studies on analysis of palliative care journals were on reporting of moral problems (ethical

issues),^[13] euthanasia,^[14] chaplains and community-based clergy,^[15,16] and, religion and spirituality^[16-18] and cancer pain.^[19] The objective of this paper was to perform a quantitative analysis of research articles on pediatric palliative care published in palliative care journals over the past 5 years.

MATERIALS AND METHODS

Search strategy and criteria

Journals indexed in MEDLINE with name “palliative” were included and searched from 2006 till 2010 for English papers with “paediatric” or “children” in the title of the paper.

Data synthesis

The total number of articles in all the selected journals was taken as N . The number of included articles (N_i) based on search criteria was compared with number of articles that had “paediatric” or “children” in the title (N_R) to obtain reporting rates ($N_i/N^0\%$) for each journal. Such an estimate provided reporting rate (RR) for pediatric palliative care. The journals were categorized broadly into multidisciplinary, medical, nursing, and other (social work) categories of palliative care journals. The included studies were then categorized into original articles and review articles. The original articles were then again grouped into qualitative and quantitative studies and both of them were then subgrouped based upon study designs. The 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].

Further, the articles on pediatric palliative care were grouped into the practice–education–research–administration (PERA) professional model of analysis: *education* – on knowledge, training, curriculum (child, parents/caregivers, physicians, nurses, other healthcare professionals, and interdisciplinary), *practice* – application, implementation, treatment/intervention (diagnosis, therapy, and prognosis), and *research* – studies on the nature and generation of evidence.

Data analysis

Descriptive analysis using frequencies for the 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, USA). Comparisons between journals and article categories were done visually.

RESULTS

Overall journals' characteristics

The study included 12 palliative care journals with a total number of 3634 articles: 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*. There were 97 articles on pediatric palliative care thus making the overall reporting rate to be 2.66% [Figure 2].

Individually, AJHPC had 16 articles,^[20-35] BMCPC had 0 article, COSPC had 0 article, IJPC had 3 articles,^[36-38] IJPN had 12 articles,^[39-50] JHPN had 1 article,^[51] JPC had 11 articles,^[52-62] JPM had 35 articles,^[63-97] JPPCP had 1 article,^[98] JSWELPC had 5 articles,^[99-103] PM had 9 articles,^[104-112] and PSC had 4 articles^[113-116] on “pediatric palliative care.” Also refer to Table 1 for respective reporting rates for journals and Figure 3 for the comparison of number of “pediatric” articles and “nonpediatric” articles between the journals.

Of the selected journals, seven were multidisciplinary (AJHPC, BMCPC, COSPC, IJPC, JPC, JPPCP, PSC), two were medical (JPM, PM), two were nursing (IJPN, JHPN), and one was other (social work, JSWELPC). The reporting rate for articles in the social work-related journal was highest at 7.5% (5/66) followed by multidisciplinary journals at 2.72% (34/1246), and nursing journals at 2.96% (13/438) [Figure 4].

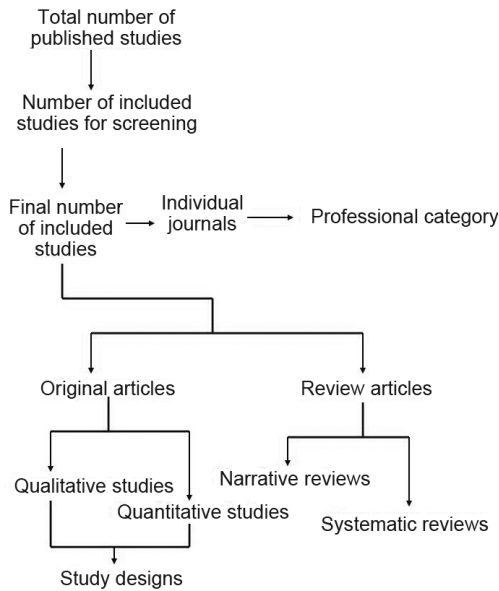


Figure 1: Schematic flowchart for data synthesis used in this study

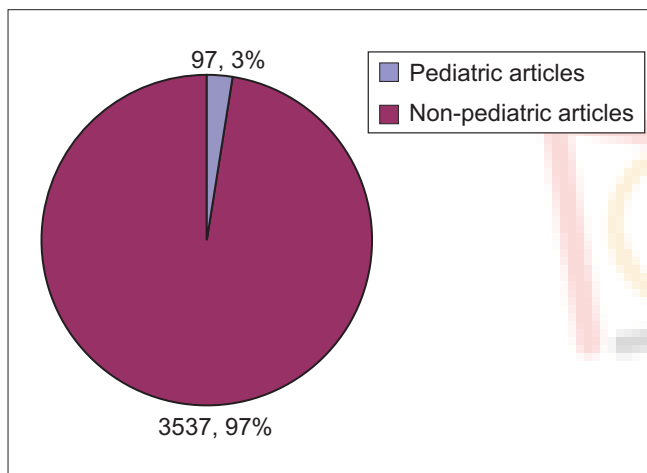


Figure 2: Overall prevalence of reporting pediatric palliative care (reporting rate) in all the palliative care journals

Table 1: Comparison of reporting rates of palliative care journals on pediatric palliative care

	Total number of articles (2006–2010), <i>N</i>	Number of articles on pediatric OR children in title, <i>N_p</i>	Reporting rate (<i>N_p</i> , <i>N_p/N</i> %)
Am J Hosp Palliat Care ^a	454	16	3.52%
BMC Palliat Care ^a	76	0	0%
Curr Opin Support Palliat Care ^a	204	0	0%
Indian J Palliat Care ^a	59	3	5.08%
Int J Palliat Nurs ^c	430	12	2.79%
J Hosp Palliat Nurs ^c	8	1	12.5%
J Pain Palliat Care Pharmacother ^b	261	1	0.38%
J Palliat Care ^a	206	11	5.33%
J Palliat Med ^b	1085	35	3.22%
J Soc Work End Life Palliat Care ^d	66	5	7.5%
Palliat Med ^b	538	9	1.67%
Palliat Support Care ^a	247	4	1.61%
Total number of articles, <i>N</i> or overall reporting rate, %	3634	97	2.66%

^aMultidisciplinary journals, ^bMedical journals, ^cNursing journals, ^dOther

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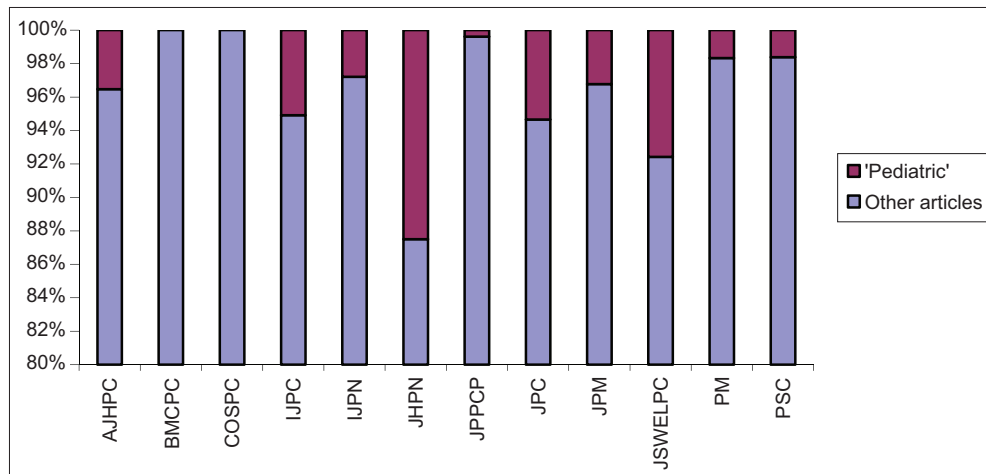


Figure 3: Comparison of reporting rates of “pediatric” articles between palliative care journals. AJHPC, *Am J Hosp Palliat Care*; BMCP, *BMC Palliat Care*; COSPC, *Curr Opin Support Palliat Care*; IJPC, *Indian J Palliat Care*; IJPN, *Int J Palliat Nurs*; JHPN, *J Hosp Palliat Nurs*; JPPCP, *J Pain 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*.

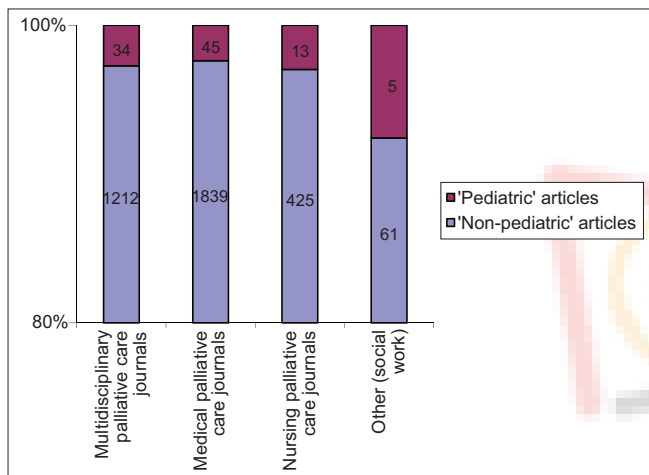


Figure 4: Comparison of reporting rates between multidisciplinary, medical, nursing, and other palliative care journals

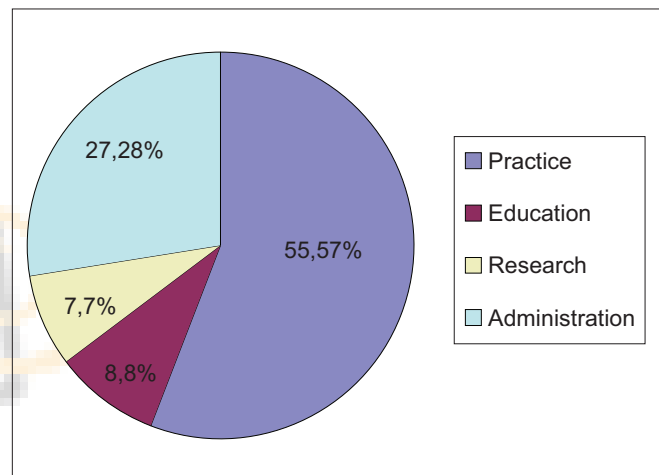


Figure 5: Distribution of categories of articles on practice, education, research, and administration (N, %) among pediatric palliative care articles

Practice, education, research and administration

Of the total 97 articles on pediatric palliative care, there were 55 articles on clinical practice, [20,22,29,33,35-40,42,44-50,52,53,55,57,59,60,63-68,70,74,75,77,80,81,83-86,92,95-100,103,106-110,112,113] 8 articles on education, [30,69,73,76,87,88,90,114] 7 articles on research, [24,28,43,56,61,104,105] and 27 articles on administration. [21,23,25-27,31,32,34,41,51,54,58,62,71,72,78,79,82,89,91,93,94,101,102,111,115,116] The relative reporting prevalence for the four categories is provided in Figure 5.

Of the 55 articles on clinical practice, 40 were original articles [20,29,33,35,37,39,40,42,45,46,48,52,57,59,60,63-66,68,70,74,75,77,80,83-85,97-100,103,106-110,112,113] and 15 were review articles. [22,36,38,44,47,49,53,55,67,81,86,92,95,96,109] There were six original articles [69,73,76,87,90,114] and two review articles [30,88] among the eight articles on education, and two original articles, [56] and six review

articles [24,28,43,61,104,105] among seven articles on research, respectively. Of the 27 articles on administration, there were 15 original articles [21,23,58,71,72,78,79,82,94,101,102,111,115,116] and 12 review articles. [25,26,31,32,34,41,51,54,62,89,91,93] The comparison of article types between four categories of pediatric palliative care articles is provided in Figure 6.

The article subcategorization and respective prevalence rates among the pediatric palliative care articles are shown in Table 2. There were 46 studies that used qualitative methods [21,23,33,37,39,40,42,45,46,48,56,58-60,63,64-66,68,69,71-73,76,78,79,82,83,88,94,97,99-103,106,107,110,111,113-116] and 17 studies that used quantitative methods [20,29,35,52,57,70,74,75,77,80,84,85,87,90,98,108,112] among the 63 original articles. Among the 34 review articles, 33 articles were narrative reviews [22,24,25-28,30-32,34,36,38,41,43,44,47,49-51,53-55,61,62,67,81,86,89,91-93,95,96,104,109] and 1 was a systematic review. [105]

Table 2: Characteristics of articles on pediatric palliative care in terms of their type of article, method of research, and study design

Total number of articles on pediatric palliative care, 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)
97	Original articles	63	Qualitative studies	46	Randomized clinical trial	0
					Nonrandomized clinical trial	2
					Cohort study	6
					Case-control study	2
					Cross-sectional study	31
			Quantitative studies	17	Randomized clinical trial	0
					Nonrandomized clinical trial	1
					Cohort study	4
					Case-control study	3
					Cross-sectional study	5
Review articles	34	Narrative reviews	33	Case report	4	
				Systematic reviews	1	

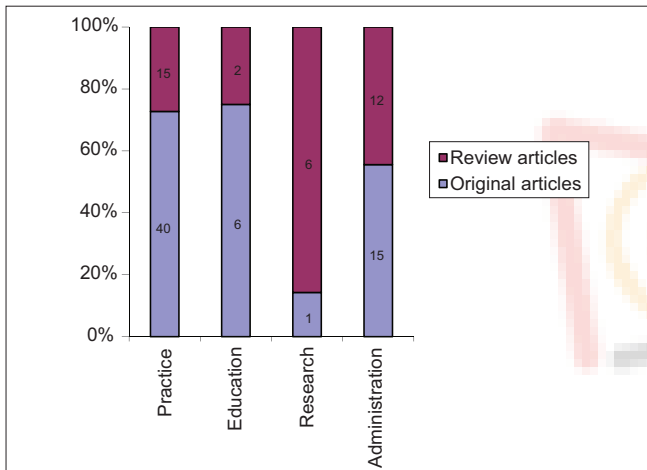


Figure 6: Comparison of types of articles among the four pediatric palliative care article categories

Figure 7 showed the comparison of qualitative and quantitative studies based upon the study designs.

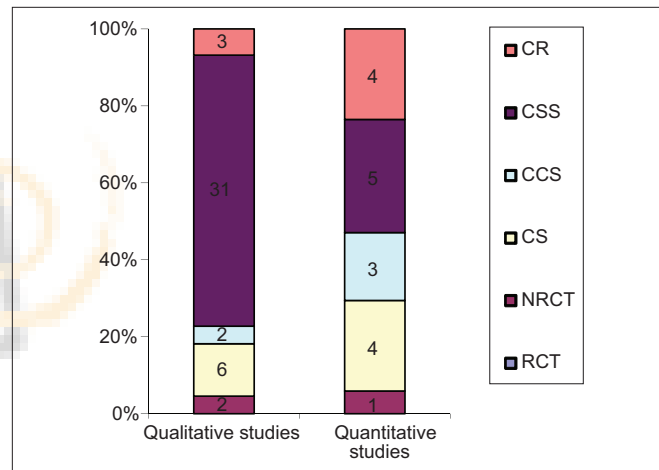


Figure 7: Comparison between qualitative and quantitative types of original articles for reporting rates of different study designs on pediatric palliative care. RCT, randomized clinical trial; NRCT, non-randomized clinical trial; CS, cohort study; CCS, case-control study; CSS, cross-sectional study; CR, case report

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 pediatric palliative care. This study included 12 palliative care journals. The previous authors Hermsen and ten Have reviewed 12 palliative care journals from 1984 to 1999,^[13,14] found reporting rate of 12% for ethical issues (458 articles) and euthanasia rate was unreported (75 articles). Hermsen and ten Have^[16] reviewed 12 journals from 1984 to 2002 and found a reporting rate

of 2% for 80 articles on spirituality, pastoral care, and religion. Flanelly *et al.*^[15] reviewed three palliative care journals from 1990 to 1999 and they found a reporting rate of 5.6% (47/838) for articles on the role of chaplains and clergy. Kumar^[19] found a reporting rate of 5.6% for cancer pain articles in 19 palliative care journals. Why this study found a much smaller reporting rate could only be due to the relatively lesser emphasis given on pediatric population, as indicated by earlier authors. This study included journals as they are indexed in MEDLINE since it is the common database for evidence search, and the past 5 years of analysis provided the information trend on reporting rates.

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The study found some interesting observations – some expected, some rather unexpected. The two unexpected observations include the following: there were higher reporting rates among social work-related and nursing palliative care journals which may be due to the lesser number of journals in respective categories, and no single randomized clinical trial (either qualitative or quantitative) or systematic review was found. The lack of systematic reviews and randomized clinical trials virtually undermines the current EBPPC since they are ranked the highest in hierarchy among the levels of evidence.

Healthcare professionals need to be aware of the relatively lesser reporting of pediatric palliative care articles in the palliative care journal literature and should shoulder the responsibility to foster better number of reporting high-quality research on the pediatric population for EBPPC. In future, such reviews could be performed with quality appraisal and identify the quality of reporting pediatric palliative care articles. Also, reviews from other related journals like pediatric journals and medical journals may yield different results. The comparison of reporting characteristics between journals based on their specialty would direct clinicians to find research appropriate to answer their relevant clinical questions during EBPPC.

CONCLUSION

The overall 5-year prevalence in reporting of articles on pediatric palliative care was low, only 2.66% among the 12 palliative care journals reviewed in this study. There were no randomized clinical trials and systematic reviews found. The study findings indicate a lack of adequate evidence base for pediatric palliative care, and further high-quality clinical trials are required to base clinical decisions for pediatric palliative care.

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