

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

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IJMHS (Jan-Jun 2016) 03 (01): 13-22 / ©Red Flower Publication Pvt. Ltd.

Abstract

Context: Palliative care practice, education, research and administration depend upon an evidence-based shared interpersonal decision-making process which in turn is based upon individual knowledge/awareness and existing research evidence. **Aims:** This study aimed to perform a quantitative analysis of research publications in palliative care journals for reporting of articles on knowledge and awareness. **Settings and Design:** Systematic review of palliative care journals. **Methods and Material:** Twelve palliative care journals were searched for articles with 'knowledge' or 'awareness' in title of the articles published from 2006-2011. The reporting rates of all journals were compared. The selected articles were categorized into assessment and treatment which were 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 and target sample populations. **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 1.50% (43/2854) and *Indian Journal of Palliative Care* (IJPC) had the highest reporting rate of 6.48% (7/108) followed by *BMC Palliative Care* (BMPC) at 3.37% (3/89), and *Journal of Palliative Medicine* (JPM) at 1.67% (11/657). **Conclusions:** The overall reporting rate for knowledge/awareness articles in palliative care journals was 1.5% and there were no randomized clinical trials and systematic reviews found. The study findings indicate a lack of adequate evidence base for knowledge/awareness in palliative care literature.

Keywords: Evidence-Based Palliative Care; Research; Journal Reporting; Publication Trend; Knowledge/Awareness.

Introduction

Palliative care in itself is a source of knowledge both for patients and caregivers and for healthcare providers and other care staff [1]. Whilst contemporary medical knowledge is sufficient to control the suffering of most of the millions of terminally patients in the world if applied appropriately, research from developing countries is therefore needed to develop, implement, and monitor the delivery of palliative care in ways that are feasible in resource-poor settings and acceptable to local populations [2].

Knowledge is built upon self-awareness with a strong behavioral dimension [3] and healthcare providers' and patients' knowledge, beliefs, or concerns about opioids, palliative care, and homecare can be potential barriers to providing quality palliative care [4]. Giardini et al [5] found that about half of their patients were unaware of their diagnosis, although, in reality, about one-third of the patients had some knowledge, albeit partial, of their diagnostic and therapeutic course. What to tell or not to tell in

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palliative care is still controversial and stems from a tailored intervention involving the patient, his/her family and professionals and silence may be more effective than intrusive communication in helping a patient to approach death with tolerable knowledge and dignity.

There is also evidence that although the nursing staffs is aware of the medical and physical care needs, they may have insufficient knowledge about the patient as a person, which is a prerequisite for individualized patient-centred care [6]. Lack of awareness, need for respite care and reimbursement policies were considered to be the main barriers to effective implementation of most hospice and palliative care programmes in the USA [7].

Assessment of needs pertaining to practice, education, research and administration is elementary for efficient provision of palliative care services [8]. A key element within the programme of reform introduced into the UK National Health Service in the 1990s has been the concept of health needs assessment, which must be undertaken by health care purchasers as a guide to the planning process. As part of a wide-ranging study of the impact of the NHS reforms on hospices and specialist palliative care services, providers' perceptions of needs assessment for palliative care were examined, and it was found that few providers had participated in the design and there were low levels of knowledge about the findings [9]. McIlfatrick [10] found that professional providers experienced difficulty in defining the term palliative care. Difficulties in communication and information exchange, and fragmented co-ordination between services were also identified. Such inadequacies of knowledge would be disastrous in two ways-affecting their role or participation as a team member and affecting their role or participation as part of the society on large.

The development of palliative care is proceeding rapidly in some areas of the world, but major problems continue to exist in several countries and regions. Comparative research evidence to inform palliative care development is limited and can be difficult to obtain, especially for resource poor settings [11]. Despite recent advances in assessment and management, major issues relating to palliative care for patients and their families remain unanswered. Several challenges face researchers in this area. There were administrative issues, including historical development, funding, academic recognition, integration of services, and cooperation among different centres [12].

Research in palliative care indicates an organized

method of pursuit of reliable knowledge [13]. At present, the translation of evidence into palliative and hospice care clinical practice lags behind emerging research evidence in palliative care at even greater rates for three critical reasons [14]: 1) the application of research results to specific clinical subpopulations is complicated by the heterogeneity of palliative care study subpopulations and by the lack of a recognized schema for describing populations or services; 2) definitional issues in service provision are, at best, confusing; and 3) fundamental research concepts (e.g., external validity, effect size, generalizability, applicability) are difficult to apply meaningfully in palliative care. Knowledge-research inter-relationship could never be under-emphasized in a scenario of evidence-informed practice [15], practice-based evidence [16] and evidence-based practice [17].

Evidence-based palliative care (EBPC) involved integrating effective research findings with clinical expertise and patient preferences towards better individualized provision of palliative care for patients [18]. One of the main causes for lack of quality in provided care for terminally ill patients in an era of evidence-informed/ evidence-based practice is the lack of adequate research evidence [19] and this may be due to four possible reasons: lesser studies being conducted on such population, publication of lesser number of studies, sociocultural and ethical issues and reporting characteristics of such studies [20,21].

Previously published studies on analysis of palliative care journals were on reporting of moral problems (ethical issues) [22], euthanasia [23], chaplains and community-based clergy [24,25], and, religion and spirituality [25-27], cancer pain [28], pediatric palliative care [29] and quality of life [30]. The objective of this paper was to perform a quantitative analysis of research articles on knowledge/awareness published in palliative care journals over the past five years.

Subjects and Methods

Search Strategy and Criteria

Journals indexed in MEDLINE with name 'palliative' were included and searched that were published from 1st December 2006 till 30th November 2011 for English abstracted papers with ['knowledge' OR 'awareness'] in [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_1) based on search criteria were compared with total number of published articles (N) to obtain reporting rates ($N_1/N\%$) for each journal.

The journals were categorized broadly into multidisciplinary, medical, nursing and other (social work) categories of palliative care journals. The included studies were categorized under assessment and treatment studies and then sub-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 sub-grouped based upon study designs. Number of articles reported in each of the final subgroups was computed and compared. The procedure of data synthesis is explained in the schematic flowchart (Figure 1). Simultaneously categorical grouping was extended to target population (healthcare professionals/students and patients/caregivers).

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).

Results

Overall Journals' Characteristics

The study included twelve palliative care journals with a total number of 2854 articles. On first level, there were 43 abstracts that were included for final analysis.

There were 43 articles that were on knowledge/awareness thus making the overall reporting rate to be 1.50% (Figure 2). The twelve journals were 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 3 articles [31-33], BMCPC had three article [34-36], COSPC had zero articles, IJPC had seven articles [37-42], IJPN had five articles [43-47], JPC had one article [48], JPM had 11 articles [49-60], JPPCP had three articles [61-63], PM had eight articles [64-71], and PSC had two articles [72,73] on 'knowledge/awareness.' Also refer to Table1 for

respective reporting rates for journals and Figure 3 for comparison of number of 'knowledge/awareness' articles and other 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 medical journals was highest at 1.64% (22/1334) followed by multidisciplinary journals at 1.43% (16/1113) and nursing journals at 1.4% (5/355).

Of all the 43 included studies, there were 41 original articles [31-67,69-72]. and two review articles [68,73]. The review article by Docherty et al [68] was a systematic review focused on caregivers' knowledge and informational needs while the other review by Tuttle [73] was a narrative review on physicians' perceptions of self-disease.

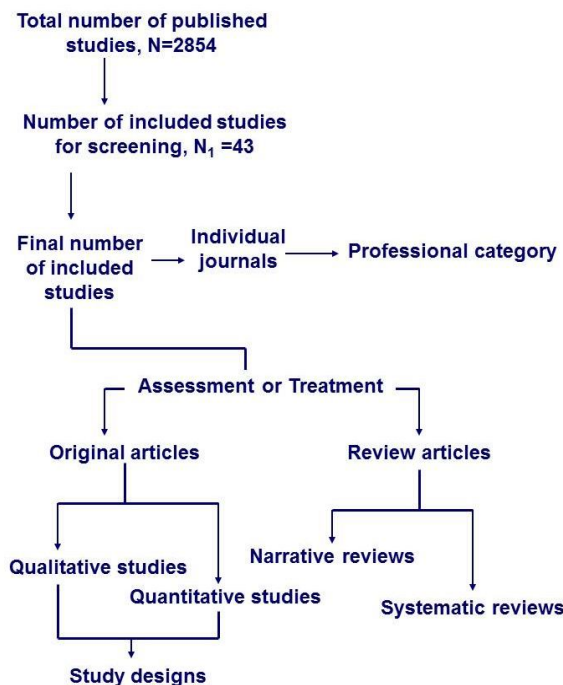


Fig. 1: Schematic flowchart for data synthesis used in this study

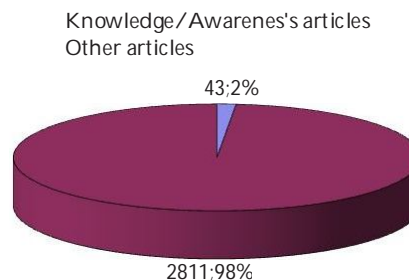


Fig. 2: Overall prevalence of reporting knowledge/awareness (reporting rate) in all the palliative care journals

The 41 original articles included 32 assessment/ evaluation studies [31-7,39,42,43,45,46,48,50-4,56-9,61-6,70-3] (31 qualitative studies [31-7,39,42,43,45,46,48,50-4,56-9,61-4,66,69,70-3] and one quantitative study [65]) and 9 treatment/ intervention studies [37,38,40,41,44,47,49,60,67]. The 31 qualitative studies included 30 cross-sectional studies [31-7,39,42,43,45,46,48,50-6,58,59,61-4,66,69,70-2] and a single case-control study [57]. The case-control study by Anderson et al [57] was on association between exposure to death and medical students' knowledge. The 30 cross-sectional studies comprised of studies targeting physicians [35,61,62,72,73], medical students[34,42,51,55,69], nursing students [39,42], allied health students [42], other care providers [31,50,54,56,58,63,64], nurses[45,46,48,72] patients [32,36,52,58,59,63,66,70,71] general public [43,53] and caregivers [33]. The comparison between the cross-sectional studies' reporting rates based upon target populations is shown in figure-4. The single

quantitative assessment study was by Nakazawa et al [65] on development and validation of palliative care knowledge test, a tool for assessing healthcare professionals knowledge.

The 9 treatment/ intervention studies (all of them were qualitative studies [37,38,40,41,44,47,49,60,67] were focused on college-going girls [37], physiotherapy students [38], medical interns [40], nurses [41], other care providers [44], physicians [47], general public [49,67] and patients [60]. The comparison between these studies based upon target populations is shown in Figure 5.

(AJHPC- Am J Hosp Palliat Care; BMCCPC- BMC Palliat Care; COSPC- Curr Opin Support Palliat Care; IJPC- Indian J Palliat Care; IJPN- Int J Palliat Nurs; JHPN- J Hospice 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; PSC- Palliat Support Care).

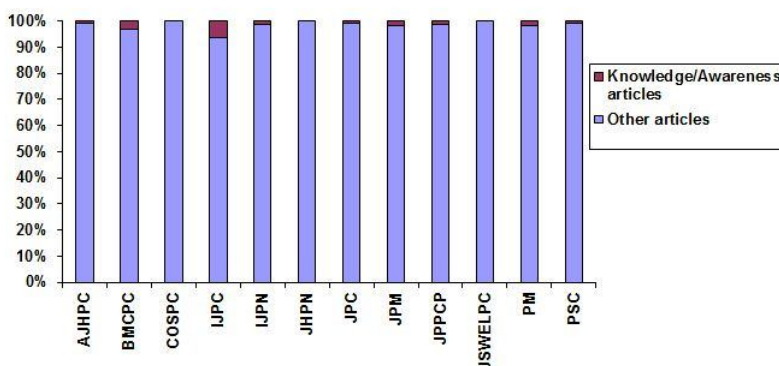


Fig. 3: Comparison of reporting rates of 'knowledge/awareness' articles between palliative care journals

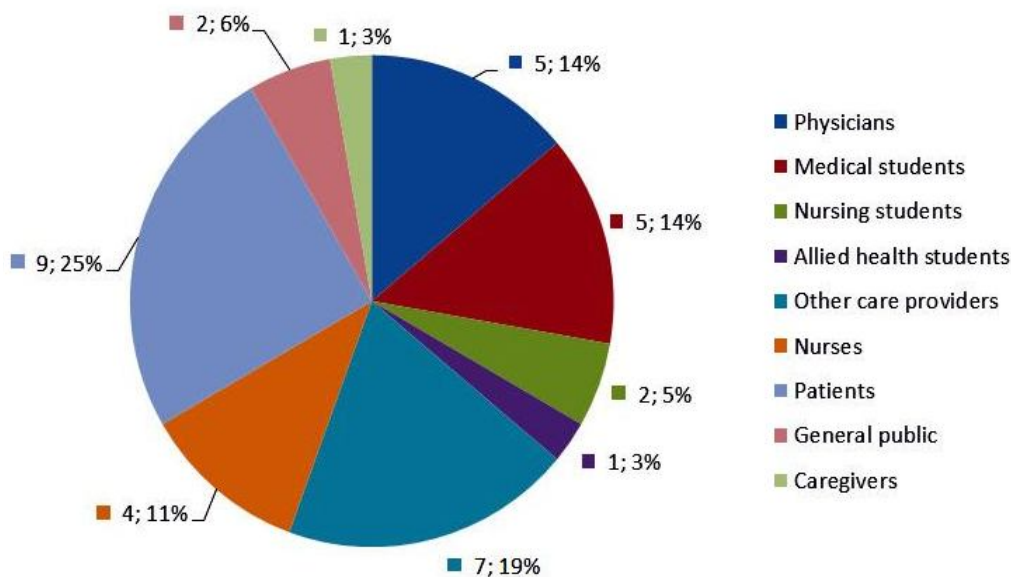


Fig. 4: Target populations in 'knowledge/awareness' articles on assessment

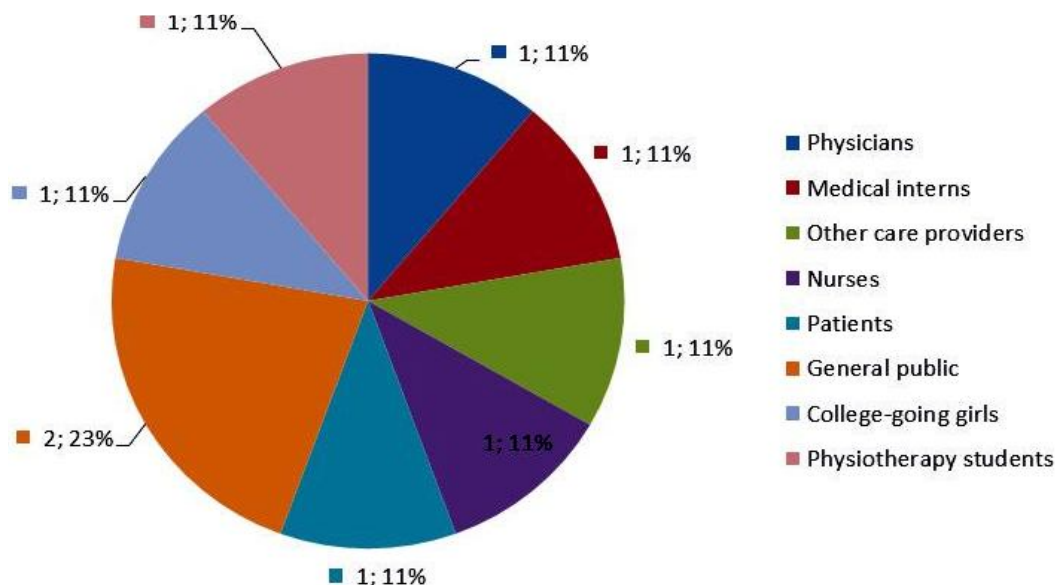


Fig. 5: Target populations in 'knowledge/awareness' articles on treatment

Table 1: Comparison of reporting rates of articles on knowledge and awareness among palliative care journals

Journals (2006-2011)	Total number of articles, N	Articles on knowledge OR awareness in Title N ₁	Reporting rate (%), N ₁ /N
AJHPC ^a	412	3	.72%
BMCPC ^a	89	3	3.37%
COSPC ^a	205	0	0%
IJPC ^a	108	7	6.48%
IJPN ^c	345	5	1.44%
JHPN ^c	10	0	0%
JPC ^a	97	1	1.03%
JPM ^b	657	11	1.67%
JPPCP ^b	196	3	1.53%
JSWEOLPC ^d	52	0	0%
PM ^b	481	8	1.66%
PSC ^a	202	2	.99%
Total	2854	43	1.50%

a- multi-disciplinary journals; b- medical journals; c- nursing journals; d- other All values are in numbers of published articles

Discussion

This review is the first of its kind focused on quantitative analysis of palliative care journals for their reporting on 'knowledge/awareness'. Knowledge is often terminologically referred associated with healthcare professionals and awareness with lay people such as general public. Research on knowledge has to be based upon qualitative methodology [74] where an individual's educational qualification and training, life's experiences, psychosocial exposure, attitudes and beliefs influence both the actual performance and self-reported levels assessed. Whilst knowledge is a result of complex cognitive and perceptual processes, the reviewed studies emphasized relatively less on the behavioral outcomes following education in the developing countries [75] where there is a higher

incidence of cancer and AIDS [76].

One of the few interesting observations of this study include: multifaceted target population (Figures 6, 7) which is essential for effective interpersonal communication and teamwork in a setting such as palliative care. Despite the overall reporting being low, original articles were more and they were on assessment rather than on interventions to improve inadequacies of knowledge. Another observation is that only one well-validated scale for objective measurement of knowledge is available, and ever since then there are no published studies using the scale [65]. Studies on healthcare professionals using palliative care knowledge test are warranted. The last observation is that the role of caregivers in palliative care could not be under-emphasized since the patient's ability for a shared decision-making is limited and hence more studies focusing on caregiver knowledge is more important.

Most of the studies found were qualitative studies and recent increase in amount of qualitative research was reported by Bailey et al [77] who conducted a critical review of qualitative research in palliative care from nursing, medicine, specialist palliative care, sociology, death studies, medical anthropology, and gerontology journals published between 1990 and 1999, and the authors found that nearly half the papers on palliative care were lacking sound methods to answer specific research questions. Thus knowledge about research would determine to a large extent, the conceptualization, data collection and publishing qualitative research evidence [78].

Amongst a few limitations such as the study sample included only palliative care journals indexed in MEDLINE, which it is assumed to be the most authentic and most widely searched database till date. Analysis of other palliative care journals, public health journals or education journals may yield different results, and comparisons between such journals' professional categories would provide a better light on availability of evidence on knowledge per se. Whether palliative care professionals refer palliative care journals the most, is another topic to be explored in future research. The search strategy used in this study would be assumed to be valid since there existed no previous validated methods to search palliative care journals. This study used the search terms in title, whilst using them in title OR abstract would have yielded different results. However, if the term is not listed in title, we could least assume that it was emphasized in the study per se. The search strategy included 'English' articles as part of per-protocol method and not for excluding non-English journals/ articles. There are also no non-English articles and/or journals in the field of palliative care in PubMed.

Previous reviews on reporting characteristics were on cancer pain, quality of life and pediatric palliative care which showed relatively higher reporting rates compared to the present study, which might be due to greater emphasis on disease or outcomes given in a palliative care research setting than on a foundational 'knowledge/awareness' domain. Knowledge about palliative care in general, and knowledge about specific issues arising in a palliative care situation like definition of death [79], euthanasia [80], presence of terminal illness [81] and the means by which knowledge is transferred to guide the practice form the basis for understanding, interpreting, communicating, documenting [82] and implementing palliative care. Two other closely related factors which determine healthcare professionals' successful delivery of palliative care

are the needs [9], attitudes and beliefs. Future research should identify reporting characteristics of such other factors to enable a better realization of the need for a better palliative care.

Healthcare professionals should shoulder responsibility to participate in knowledge exchange through inter-personal relationships in all aspects of palliative care [83]. In India, there is an ever-growing need for awareness in general population [84] for effective knowledge translation [85] using a Gold Standards Framework (GSF) [86]. The methodological challenges [87] of researching the healthcare experiences of palliative care patients are: defining a 'palliative care patient'; negotiation of access via healthcare professionals, the choice of appropriate data collection tools and methods; the consequences of high attrition rates, and frequent use of retrospective surveys of bereaved relatives. The heterogeneity of the palliative care population represents structural challenges to research methodology, including study design, informed consent (and ethical issues in general), assessment and classification of symptoms and signs, as well as practical issues in the clinic [88]. Conducting research on families of individuals receiving palliative care has conceptual challenges [89]: issues include defining the family, determining the unit of analysis in the level of inquiry, and identifying pathways to knowledge about the family. Some of the key areas of research [87] include: patients' and families' experiences of research participation, the impact of being approached on those who decline, how the characteristics of those who participate differ from those who do not and the likely impact of this on findings.

Performing quantitative analysis of articles provide us with information regarding the actual content-related prevalence from an evidence-informed perspective. There were many reviews of palliative care journals published over the years, on diseases/symptoms such as HIV/AIDS [90], cancer pain [28] and cancer-related fatigue [91]; on populations such as pediatric [29]; on research such as systematic reviews [92], randomized controlled trials [93] and validation studies [94]; on outcomes such as quality of life [30] and, on behavioral aspects such as attitudes [95] and death [96].

Conclusion

The overall 5-year prevalence in reporting of articles on knowledge/awareness was 1.5% 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 knowledge/awareness in palliative care literature and further high quality clinical trials are required to base decisions for addressing health-related issues of knowledge and awareness.

Acknowledgments

None

Conflicts of Interest

None identified and/or declared.

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