Original Article

Disparities in the Contribution of Low- and Middle-Income Countries to Palliative Care Research

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Abstract

Context. Important aspects of the palliative care needs of patients from low- and middle-income countries (LMIC) are largely unexplored. About 44 million of the 56 million annual deaths worldwide occur in developing countries, and it is estimated that more than 33 million of those concerned would benefit from palliative care. In this context, the understanding of specific social and cultural needs is fundamental to the development of appropriate health policy and clinical practice concerning palliative and end-of-life care.

Objectives. This study aims to answer the question: what are the contributions, in terms of generation of knowledge, of LMIC to the published palliative care literature?

Methods. A bibliometric analysis was conducted in Medline® and EMBASE® (to June 2008). Articles were included when either the first author (institutional affiliation or contact address) or the data collection was derived from LMIC, as defined by criteria of the World Bank. Excluded were articles done in migrant and non-palliative care populations.

Results. The literature search resulted in 845 references. In total, 245 articles coming from LMIC were identified, being published by 34 LMIC (27.3% of LMIC). The first publications appeared in 1982. The study shows a rather modest contribution of publications from LMIC. However, the volume of publications within LMIC is distributed unequally: upper-middle-income countries published almost half of the articles (46.9%), whereas only 11% of the publications came from low-income countries. In contrast, 104 LMIC (72.7% of LMIC) do not have any registered publications. Surprisingly, 25% of the articles with data from LMIC have been done and published by high-income countries. Reasons for the underrepresentation, as well a possible correction of this imbalance, are discussed.

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Conclusion. Palliative care research should be a priority in LMIC, where many patients could benefit tremendously from it, and publication of findings in these countries should be encouraged.

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Key Words

Bibliometrics, disparities, palliative care, research, low- and middle-income countries

Introduction

The allocation of resources for research in biomedicine has a direct impact on the progress of health science and the distribution of health.[1] Health research is crucial for evolving solutions to specific health problems and optimizing health policy and services; it contributes to the improvement of care for individual patients and carers by giving evidence for decision making. It also contributes to the study of wider dilemmas in medicine and health care.[2]

Global investments in research and development (R&D) for health have increased by 0.8% (corresponding to US$21 billion) since 1998[3] and currently represent approximately 15% of the global investment in all sectors.[4] However, the Global Forum for Health Research[5] has denounced the enormous gap in the research output between high-income countries (HIC) and low- and middle-income countries (LMIC), which is often referred to as the 10/90 gap. There are many challenges involved in dealing with this issue if the problem is to be overcome. Although middle-income countries (MIC) are increasing their research investments, health research in low-income countries (LIC) remains limited and is still funded largely from external sources.[6] The correction of this disequilibrium is a priority on the global health research agenda.[7]

The need for research relating to the care of those with advanced illness and close to death was recognized from the origins of the modern hospice movement and also has accompanied the young specialty of palliative care.[2] Research is fundamental to improving the care of patients and developing palliative care as an evidence-based specialty.[8] The potential of empirical knowledge to inform stakeholders, as well as the public, about dying and practices on the adequate control of pain and suffering depends on the quality and quantity of the research available. Research in palliative care is underrepresented in international comparisons with other medical fields,[9] although in many industrialized countries, growing attention is given to the specialty and consequently to research in this field.[10]

Patients with advanced, irreversible disease need palliative care in every country of the world. There are currently some 56 million deaths in the world per year. About 44 million of these occur in developing countries, and it is estimated that more than 33 million people would benefit from palliative care before their death.[11] According to the World Health Organization (2005), 7.6 million people died of cancer. More than 70% of those deaths occurred in LMIC.[12] Almost three million people in the world died with human immunodeficiency virus/acquired immunodeficiency syndrome in 2006, most of them in LIC.[13] The need for palliative care to prevent unnecessary pain and suffering is, therefore, especially pronounced in developing nations.[11] Although it has been advocated that access to palliative care should be recognized as a human right,[14] palliative care services are available only in half of the countries of the world.[15] Furthermore, it is known that inequities in health research have a relationship to inequities in health.[16]

Central aspects of palliative care, such as the emotional, social, and spiritual needs of patients and/or relatives; the pain and other symptoms experienced; meanings attached to the disease; and the wider suffering endured by patients from LMIC at the end of life, including place of death, are largely unexplored at the level of systematic research.[17–19] However, palliative care is a culturally sensitive issue and requires a specific approach that reflects these diverse realities, including those at the local health system level. This understanding is fundamental to the development of both appropriate health policy and clinical practice.

Research published in leading journals for health policy and palliative care practice may

Table 1
Literature Search

Electronic Database Searched	Search Term Used (Using [MeSH Terms] or [TIAB] and "Explode" Function. Limit "Only with Abstract")
EMBASE® (1947 to June 2008), searched July 6, 2008 MEDLINE® (1950 to June 2008), searched July 10, 2008	Terms related to geographic localization: "Latin America" "Central America" "Caribbean Region" "South America" "Africa" "Asia" "Atlantic Islands" "Pacific Islands" "Indian Ocean Islands" "Arctic Regions" "Antarctic Regions" "Mexico" "Albania" "Armenia" "Azerbaijan" "Belarus" "Bosnia and Herzegovina" "Bulgaria" "Croatia" "Georgia" "Latvia" "Lithuania" "Macedonia" "Montenegro" "Poland" "Romania" "Russian Federation" "Serbia" "Ukraine" "Yugoslavia" "non-Western cultures" with terms related to palliative: "Hospice*" "Palliative Care" "Terminal Ill" "Terminal care" "End-of-life care"

help to highlight needs and priorities, demonstrate effectiveness, and thus help to implement and develop palliative care. Publications are a "thermometer" of scientific activity in the international scientific community. The number of published articles and their citations (reflected in the impact factor) are an acknowledged indicator to assess the quality and quantity of research and to set them in an international context.[20]

This study looks at the contribution of LMIC to the palliative care literature, with a special focus on research studies. It seeks to describe the situation, to identify gaps, and to help focus on country-related differences in priorities concerning palliative care. In addition, it aims at answering the following questions: What is the contribution, in terms of generation of knowledge, of LMIC to the palliative care literature published in the international medical literature? And which LMIC do perform this research?

Methods

A bibliometric analysis was conducted in Medline® and EMBASE® (to June 2008). Table 1 outlines the search strategy. This strategy yielded a total of 845 hits, which were downloaded into an Endnote® (software) file. Titles and abstracts were screened in relation to the inclusion criteria. Articles were included when either the first author (institutional affiliation or contact address) or the data collection was derived from LMIC, as defined by criteria of the World Bank.[21] The affiliation of the first author was used as an indicator of the origin of the paper, assuming that he/she did the main work and occupied an important place in the authorship. Multinational studies were counted if the data collection was realized in at least one LMIC. Excluded were 600 references as irrelevant according to predefined criteria (editorials and research done in migrant and nonpalliative care populations). The selected articles were analyzed by two authors, and the information was extracted into a database, including information about affiliation of the first author, field research, issue, study design, sample target, and publication (journal, year). Disagreements were discussed with the other authors. Data were analyzed using the Statistical Package for the Social Sciences (SPSS) for Windows (SPSS, Inc., Chicago, IL, USA).

Results

The literature search resulted in 845 references. In total, 245 articles coming from LMIC were identified, which were published in 126 journals (Fig. 1).

The first publication identified was published in 1982.[22] After this, the number of publications grew slowly each year, with little fluctuation. Since the 1990s, however, the quantity of publications has risen constantly, reaching the maximal number of 42 in 2007 (Fig. 2). The mean number of publications per year in the period 1982–2007 was 12.

Researching Palliative Care in or with LMIC?

One-quarter (25%) of the identified articles with data from LMIC were published by first authors coming from HIC. The United States contributed 9.8% ($n = 24$) of the publications and the United Kingdom 5.3% ($n = 13$). Other HIC with contributions to the literature on palliative care in LMIC were Australia (2.9%), Canada (2.4%), Belgium (0.8%), Germany (0.8%), Switzerland (0.8%), Italy (0.4%), The Netherlands (0.4%), Norway (0.4%), and Singapore (0.4%) (Fig. 3). There was only one paper going in the other direction: an author from Grenada (upper-middle-income country [UMC]) undertook a study in the United Arab Emirates (HIC).

Almost half of the articles (46.9%) were published by authors from UMC, whereas only 11.0% of the publications came from LIC. The countries with the highest number of publications were Brazil (9.0%), followed by India and South Africa (8.6%), Argentina (6.1%), and Turkey (4.9%)—all of these are UMC. In contrast, 104 LMIC did not have any registered publications.

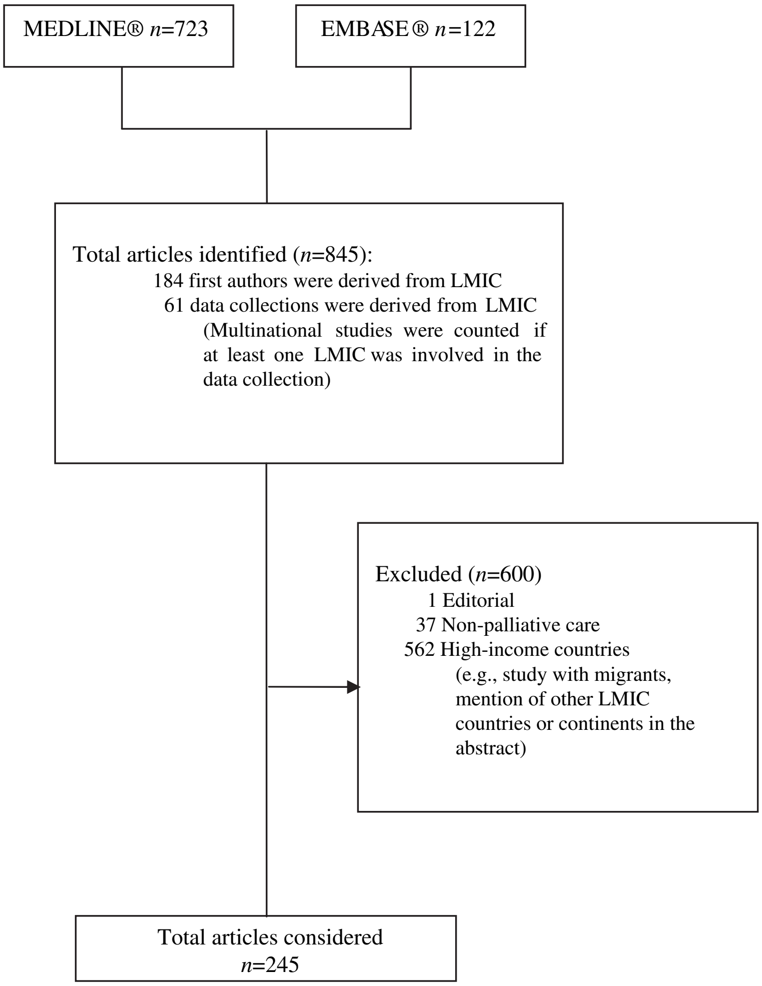

Fig. 1. Flow chart summarizing number of studies identified and ultimately included.

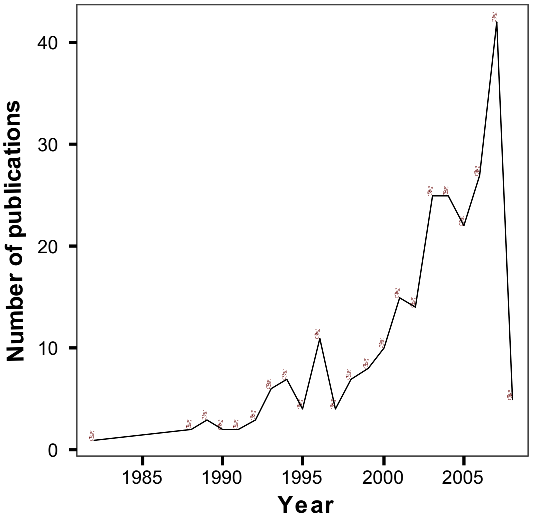

Fig. 2. Publications from LMIC per year (through June 2008).

The percentage of papers with first authors from low-middle-income countries (LMC) was 17.1% ($n = 27$); the percentage from LIC was 11.1% ($n = 42$). There was an upward trend in the number of publications in the UMC and in HIC publications conducted in LMIC. However, the number of publications from LIC and LMIC remained around five per year (Fig. 4).

Articles published from LIC were regularly built on data derived from those regions. Seventeen percent involved more than one country in projects such as multicenter studies or intercultural comparisons. A small percentage (3.3%) consisted of articles not related to a specific region but with general and theoretical content applicable to the whole field (Table 2).

Publications from LMIC: International Comparison

A simple search was undertaken on Medline® (with the following strategy "Terminal Care" or "Palliative Care" or "Terminally Ill" or "end of life care" or "Hospice care" or "Hospices" using [MeSH Terms], [TIAB], and "Explode" function). Limiting by "only with Abstract" resulted in a total of 19,122 titles. Taking this figure as a denominator describes 1.3% ($n = 245$) of the publications on palliative care in the world coming from LIC and MIC.

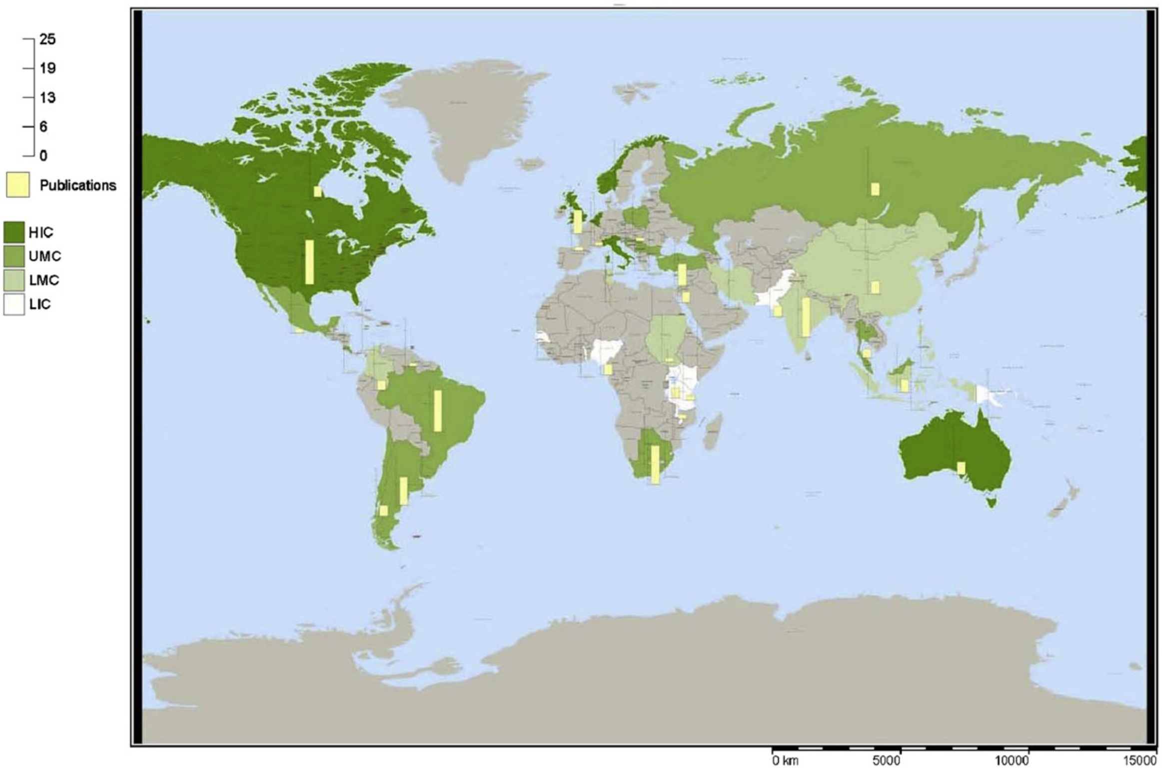

Fig. 3. Number of publications by origin of the first author and place of research (according to World Bank income groups).

Where Is Palliative Care Research from LMIC Published?

The impact factor may be used to describe the importance of a journal to its field. Only 46 of the journals (36%) with publications from LMIC had any impact factor.

The *Journal of Pain and Symptom Management* published the most articles ($n = 24$, impact factor = 2.324) followed by the *Journal of Pain & Palliative Care Pharmacotherapy* ($n = 11$, impact factor = 0).

To analyze this aspect, the impact factor of journals was categorized into the following three groups: high impact factor (>4), medium impact factor (2−4 inclusive), and low impact factor (<2).[23] UMC and HIC publish more in impact factor journals, whereas LIC publish more in journals with no impact factor (Table 3).

The Language of Palliative Care Research

English was the predominant language in the publications ($n = 207$, 85%), although publications in other languages, such as Spanish ($n = 18$, 7.3%), Portuguese ($n = 8$, 3.3%), Russian ($n = 6$, 2.4%), French ($n = 4$, 1.6%), and Polish ($n = 1$, 0.4%) were identified (Table 4). Only three journals in a language other than English had any impact factor.

What Kinds of Studies Are Published?

In total, 142 (58%) of the publications reported empirical studies. A considerable number of quantitative studies (44.9%) were

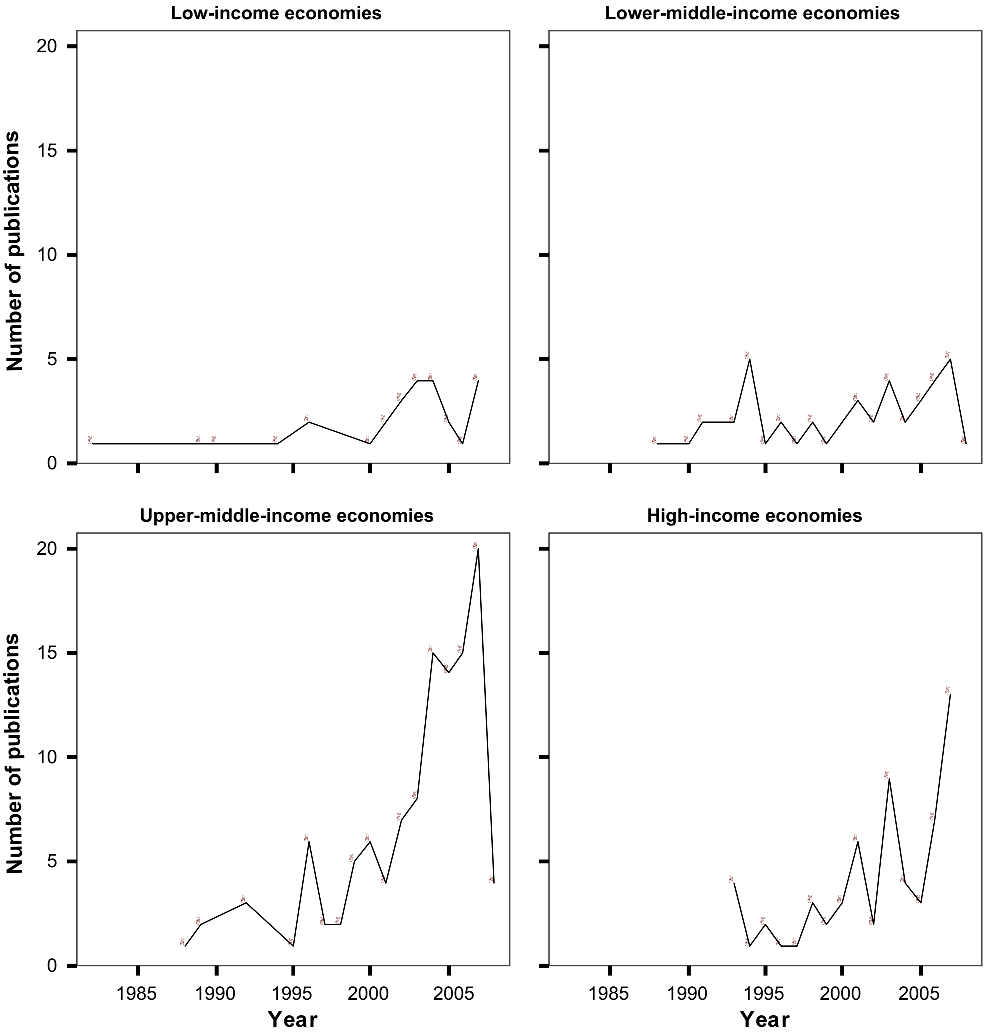

Fig. 4. Economies vs. number of publications from low- and middle-income countries per year.

Table 2
Origin of the First Author by Place of Research According to World Bank Income Groups

	Author				
Research Place	LIC, *n* (%)	LMC, *n* (%)	UMC, *n* (%)	HIC, *n* (%)	Total, *n* (%)
LIC	23 (85.2)	—	—	7 (11.5)	30 (12.2)
LMC	—	38 (90.5)	—	13 (21.3)	51 (20.8)
UMC	—	—	103 (89.6)	10 (23.0)	113 (46.1)
HIC	—	—	1 (0.9)	—	1 (0.4)
Multicentric/partnerships	3 (11.1)	4 (9.5)	7 (6.1)	28 (45.9)	42 (17.1)
No localization	1 (3.7)	—	4 (3.5)	3 (4.9)	8 (3.3)
Total	27 (100)	42 (100)	115 (100)	61(100)	245 (100)

identified, half of them cross-sectional studies. Questionnaires were the most common data collection method. Prospective studies (inclusive of quasi-experimental studies) accounted for 12.6%, whereas randomized controlled trials (RCTs) amounted to 2.0%. Retrospective studies were reported in 7.8% of the cases (Table 5).

Interestingly, the use of mixed methods (4.1%) began to appear by the late 1990s. Qualitative research methods were used in 9% of studies (particularly in Brazil) and used interviews almost exclusively (Fig. 5).

The source of data within the empirical studies (Table 6) was predominantly patients (34%), followed closely by health professionals (31%). Medical records were used in 16% of the studies, and the relatives were studied in 6% of the research.

LIC and LMC used predominantly quantitative methods, especially cross-sectional studies, whereas UMC used a broad spectrum of designs, such as qualitative methods and mixed methods (Table 7). Along with quantitative studies, they carried out RCTs also. Of the studies conducted by HIC, 60% were quantitative (cross-sectional, prospective, and RCTs).

RCTs are considered to have the highest importance in the delivery of scientific evidence. However, they are only very rarely conducted in palliative care and only by HIC ($n=2$) and UMC ($n=3$).

A large percentage of the publications consisted of nonempirically based articles such as reports (16.7%), reviews (14.3%), and position papers (7.3%).

What Is Researched?

A content analysis of the main research topics (Table 8) showed that one-third of the articles were concerned with palliative care services and were focused on documenting evolution, evaluating the benefits, assessing needs and access, and analyzing legislation and costs. Articles about service provision were mostly published in the form of a report ($n=60$, 24.4% of all publications). For example, in 2007, the *Journal of Pain and Symptom Management* published a public health issue that included reports from LIC and MIC.

Twenty-three percent of the articles dealt with end-of-life decision making (euthanasia and withdrawal of treatment), with consideration of such aspects as practices and attitudes. Of these, 12.7% ($n=31$) were quantitative studies and 9.4% ($n=23$) were nonempirically based articles.

Palliative antineoplastic treatment was also an important issue in 14.3% ($n=35$) of the articles, with radiotherapy and surgery as the most examined aspects. A smaller percentage of the articles focused on the palliative care team ($n=15$, 6.1%), investigating the knowledge and attitudes of medical doctors and nurses, followed

Table 3
IF of Published Papers from LMIC and the Origins of the Author According to World Bank Income Groups

Papers with IF	LIC, *n* (%)	LMC, *n* (%)	UMC, *n* (%)	HIC, *n* (%)	Total, *n* (%)
No IF	19 (70.4)	21 (50.0)	77 (67.0)	25 (41.0)	142 (58.8)
Low IF (<2)	4 (14.8)	9 (21.4)	20 (17.4)	16 (26.2)	49 (20.0)
Medium IF (2−4)	2 (7.4)	8 (19.0)	12 (10.4)	14 (23.0)	36 (14.7)
High IF (>4)	2 (7.4)	4 (9.5)	6 (5.2)	6 (9.8)	18 (7.3)
Total	27 (100)	42 (100)	115 (100)	61(100)	245 (100)

IF = impact factor.

Table 4
Language of Publication from LMIC

Language	*n*	%
English	207	84.5
Spanish	18	7.3
Portuguese	8	3.3
Russian	6	2.4
French	4	1.6
Polish	1	0.4
English, French, and Russian	1	0.4
Total	245	100.0

by research on job satisfaction and distress. Research regarding patients and relatives accounted for 5% ($n = 12$) of the articles; most qualitative studies were on this topic ($n = 9$).

Analysis of pain and symptom management was the subject of 4% ($n = 10$) of the articles. There were fewer publications on ethics (including dignity) (2.4%), outcomes (1.6%), and spirituality (1.2%). Only 2% ($n = 5$) of the publications dealt with cultural issues.

Discussion

Several methodological challenges were posed by this research. The description of the methods used in the analyzed articles was sometimes unsatisfactory, and some of the articles contained contradictory information about the study design. The classification of the articles according to the research design, as well as the topic, was not always unequivocal and required discussion with a second author. Moreover, the number of findings in this study was slightly reduced by excluding titles where no abstract was available.

Low Proportion of International Representation

Nevertheless, this bibliometric analysis shows a clear underrepresentation in the contribution of publications from LMIC. The mean number of annual publications in the period from 1982 to 2007 is 12, despite the population of LMIC constituting 85% of the global population. This is even more dramatic if only research articles are considered. This disequilibrium has been reported in other fields of biomedical publications, such as editorial boards,[24] leading journals in psychiatry[25–27] and hematology,[28] as well as in the overall contribution of publications in high-impact journals.[29] The average contribution to the medical literature of the Rest of the World (RoW, i.e., the whole world excluding Euro-American countries) and to the research literature in the five leading journals is 6.5%.[29] In 2002, the participation of members from medium- and low-human development index (HDI) countries was zero for *Annals of Internal Medicine*, *Journal of the American Medical Association*, and the *New England Journal of Medicine*, whereas the *British Medical Journal* had 19% (5 of 26) of editorial board members from medium HDI, and *The Lancet* had one from medium-HDI and two from low-HDI countries.[24] Searching in ISI Web of Science database (1992–2001) health-related journals, the contribution from LMIC was 6%.[25] In the six leading journals in psychiatry, Patel and Sumathipala in 1996–1998 found 6% ($n = 173$) of articles from RoW[27] and only 4% ($n = 98$) from LMIC in 2002–2004.[26] Only China published 35 articles (1.0%) in the seven major clinical journals with the highest impact factors in the field of hematology, based on ISI Journal Citation Reports in 2002.[28]

The volume of all medical publications from Asia, Latin America, and Africa increased slightly in the period between 1990 and 2000. However, the total proportion of publications coming from LIC and LMC decreased by 0.3% in that time, resulting in 1.7% for LIC and 2.6% for LMC.[30] In the field of palliative care, there has been an increase in the total number of

Table 5
Study Design in Publications From LMIC

Primary Studies			
Quantitative Studies, *n* (%)	Mixed Methods, *n* (%)	Qualitative Studies, *n* (%)	Nonempirical Studies, *n* (%)
19 (7.8) (retrospective) 54 (22.0) (cross-sectional) 31 (12.6) (prospective) 5 (2.0) (RCT)	10 (4.2)	22 (9)	41 (16.7) (report) 35 (14.3) (review) 18 (7.3) (position paper) 6 (2.4) (case report) 3 (1.2) (others)
110 (44.9)	10 (4.2)	22 (9)	104 (42.4)

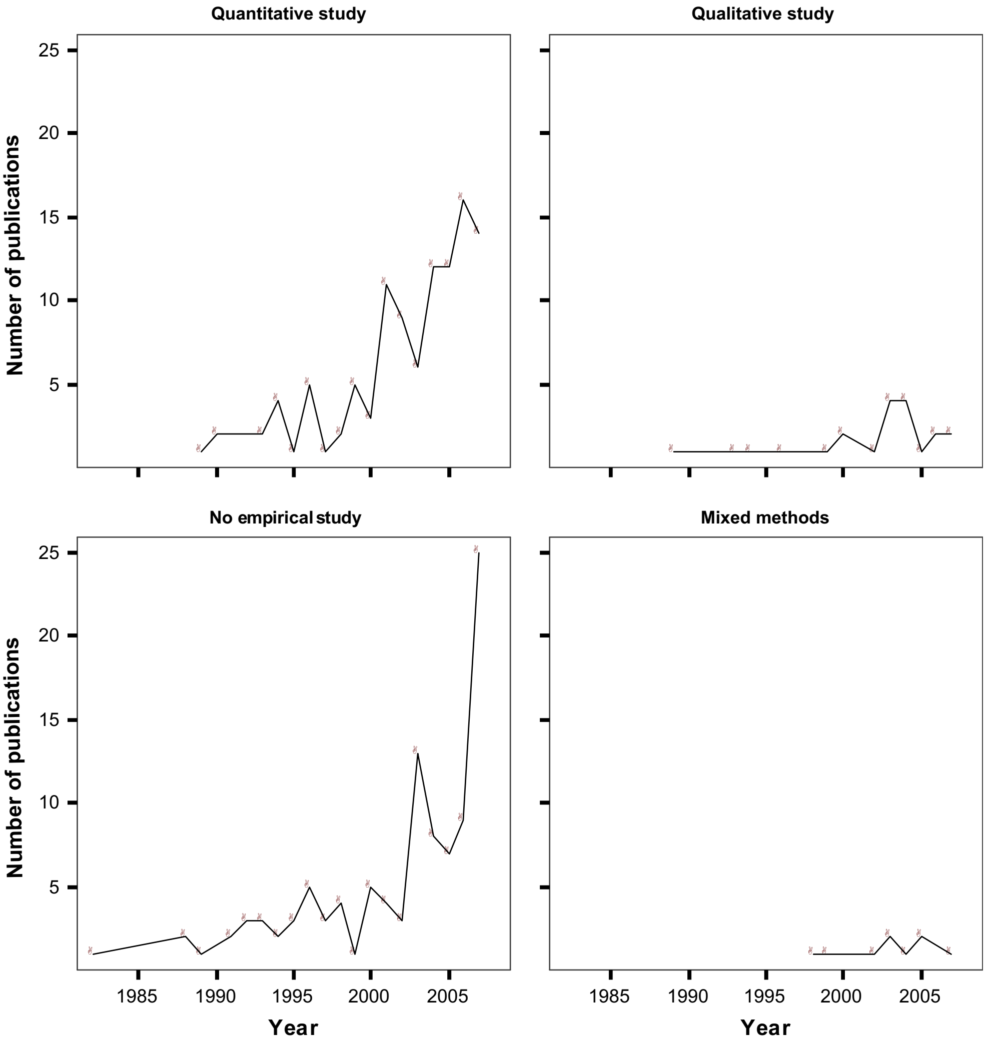

Fig. 5. Number and kind of publications from low- and middle-income countries per year (2008 was excluded to minimize bias).

publications in recent years, mainly coming from UMC and HIC (conducted in LMIC). The contribution of LIC and LMIC remains minimal.

Among the LMIC, the relationship between number of publications and economic ranking remains.[30] So the majority of publications, and more specifically, of the research papers, came from UMC countries such as Brazil, India, South Africa, Argentina, and Turkey. Rahman and Fukui[31] found a significant relationship between publication per million population and the gross national product per capita, and R&D expenditure.

HIC published 25% of the palliative care articles based on data from LMIC. Often the relevance and methods whereby data were collected are not clarified, and the results have little direct use. According to an informant from Ghana discussing other areas of research: “The importance is that information is available here; much research is processed abroad, reports are written and published abroad, and we don’t even get a copy.”[32]

A large number of publications did not refer to research. Within the reports of empirical research, the method used most frequently was quantitative design. Cross-sectional studies were the most popular design, most likely because of their feasibility and low resource requirements. RCTs were few and conducted exclusively by HIC or UMC. The relative neglect of longitudinal research, and especially RCTs,[33,34] is a big limitation in palliative care research in general.[35]

Table 6
Source of Information Used in the Research Studies

Source of Information	*n*	%
Patients	48	34.4
Health professionals	44	33.6
Medical records	22	15.7
Relatives	8	5.7
More sources	6	4.3
Others	8	5.7
Total	140	100.0

The use of qualitative research methods is rather new in health research in general and consequently in palliative care research. Qualitative methods applied in palliative care research are mostly limited to interviews, sometimes with theoretical backgrounds such as grounded theory or phenomenology. Similar results are reported in the journal *Palliative Medicine*.[10]

An analysis of the databases from the ISI showed an overrepresentation of English language journals and concluded that scholars from other countries tend to publish less in English and more in their domestic language,[36] following the "linguistic hegemony" hypothesis.[37,38] This criticism of the "English-bias" in Medline® and EMBASE® also could be true for this study. Research from LMIC may be published predominantly in the "gray literature," for example, in local and regional journals, "which are not easily accessible"[39] and which are not listed in the researched database, because this database does not exhaustively list internationally accessible literature. Furthermore, writing in English could be difficult for non-native English speakers. A good solution was the so-called open access initiatives,[40,41] which could facilitate up-to-date evidence for palliative care, especially in developing countries. This requires a better and cheaper access to the Internet than what is available at present.[42] However, the information flow should not be one way from HIC to LMIC.[42] Another possibility would be the listing of local and regional journals in an open-access research database. Dual publication (international and local journals) also could be possible, even considering a potential breach in the copyright legislation.

The landscape of interests was quite different in LMIC in comparison with the areas in palliative care research that have been highlighted by Richards et al.[2] (Table 9). "Specialist palliative care service" (including hospice and palliative care in hospitals) was researched most often (11.4%), followed by "needs/experience of patients" (7.1%) and "policy issues" (including opioid availability). In contrast to Richards et al., topics such as "end-of-life decisions" and "palliative treatment" were well researched, with 24.3% and 10.7%, respectively. "The palliative care team," including knowledge, practices, and experience (such as distress or job satisfaction), was frequently investigated. Other essential topics mentioned by Richards et al., such as "pain and symptom control," "assessment tools," or "place of death," were investigated less frequently and seemed to be covered inadequately.

A big gap was evident for "psychological and spiritual issues" and "preferences and trajectory of deaths in different cultural settings;" studies on ethnic, cultural, and socioeconomic diversity were missing altogether. These are areas that have to be studied by local researchers from data collected within the region using tools that are sensitive to the regional context. This requires time, financial support, and a qualitative orientation in research methodologies, all of which are largely unavailable in resource-poor settings. The use of qualitative methods beyond interviews, such as ethnographic research, discourse analysis, or conversation analysis, could enrich the gain of knowledge.

Table 7
Origin of the First Author According to World Bank Income Groups Related to Study Design

Study	LIC, *n* (%)	LMC, *n* (%)	UMC, *n* (%)	HIC, *n* (%)	Total, *n* (%)
Qualitative	1 (5.0)	1 (4.8)	12 (17.4)	7 (23.3)	21 (14.9)
Quantitative	18 (90.0)	21 (95.5)	53 (76.8)	18 (16.4)	110 (78.0)
Mixed methods	1 (5.0)	—	4 (5.8)	5 (16.7)	10 (7.1)
Total	20 (100)	22 (100)	69 (100)	30 (21.3)	141 (100)

Table 8
Study Design and Research Issue

Themes vs. Study Design	Quantitative Studies, *n* (%)	Mixed Methods, *n* (%)	Qualitative Studies, *n* (%)	Nonresearch, *n* (%)	*n* (%)
Health care service	18 (7.3)	**8 (3.3)**	2 (0.8)	**60 (24.4)**	**88 (35.9)**
End-of-life decision	**31 (12.7)**	1 (0.4)	3 (1.2)	23 (9.4)	58 (23.7)
Antineoplastic treatment	28 (11.4)	—	1 (0.4)	6 (5.8)	35 (14.3)
Knowledge, attitude of the team	11 (4.5)	—	4 (1.6)	—	15 (6.1)
Experiences, attitude of patients and carer	1 (0.4)	1 (0.4)	**9 (3.7)**	1 (0.4)	12 (4.9)
Pain/symptom control	6 (2.4)	—	—	4 (1.6)	10 (4.1)
Ethics	2 (0.8)	–	1 (0.4)	3 (1.2)	6 (2.4)
Epidemiology/illness	5 (4.5)	—	—	—	5 (2.0)
Communication	3 (1.2)	—	1 (0.4)	1 (0.4)	5 (2.0)
Education	1 (0.4)	—	—	3 (1.2)	4 (1.6)
Outcome	4 (1.6)	—	—	—	4 (1.6)
Spirituality	—	—	—	3 (1.2)	3 (1.2)
Total	110 (44.9)	10 (4.1)	21 (8.6)	104 (42.2)	

Reasons for Underrepresentation

Analyzing the literature, we can suggest several hypotheses for the very low representation of publications from LMIC and especially of research articles. Part of this discussion is extrapolated from the analysis of publications for medicine in general.[24,29,43–46] In "palliative care research in LMIC," two great challenges coalesce: the problems of health research in poor countries and the difficulties in palliative care research that are not related to resources.

Researching in a Resource-Poor Setting. A general obstacle in the research by LMIC is the restricted research capacity, including limited institutional and regulatory frameworks, missing infrastructure, low funding, and poor human resources trained to conduct and publish research.[15,16,19,20,39,45,47] In addition, journal editorial boards and reviewers may latently reinforce publication bias by "institutional racism"[24,27,48]—a phenomenon that might even be aggravated by the minimal participation of LMIC in editorial boards. This is defined "as any system (usually a combination of institutions and people) that systematically discriminates against others on the grounds of race or creed, and can occur 'when the policies and practices of an organisation result in different outcomes for people from different racial groups' (…) 'without intention or knowledge'."[48]

Table 9
Research Topics in Palliative Care According to Richards et al.,[2] Compared with the Research Found in LMIC

General Research Areas	LMIC (%)
Specialist palliative care services	11.4
Needs/experience of patients	7.1
Policy issues	6.4
Communications skills	4.3
Prevalence of symptoms	4.3
Pain control	2.1
Studies of carers	2.1
Assessment tools	1.4
Control of other symptoms	1.4
Place of death	1.4
Conventional care	0.7
Bereavement	—

Moreover, it is possible that the themes selected from LMIC do not attract interest and may be considered irrelevant to readers who do not work in LMIC. This "scientific colonialism,"[49] expression of the underlying assumption that research, ideas, and methods from Western societies are automatically considered to be of international significance, has also been challenged.

Researching in Palliative Care. General causes for low levels of research in palliative care[8,33,50] also are reflected in the output of research from LMIC. There are ethical[51] and methodological difficulties,[47] such as problems with sample size and attrition,[8,35,52] the need for surrogate respondents,[35] and appropriate outcome instruments.[8,18,19] Palliative care is a young specialty, and its research infrastructure is still not established.[53] Being a young field in health care, there are few previous models to support new research and to facilitate funding. Research, especially in palliative care, requires methodological precision because of its inherent complexity, which includes ethnic diversity and cultural and religious background, as well as its multidimensionality (physical, emotional, social, and spiritual dimensions).[47,51,54]

Palliative Care Research in LMIC. There are some specific problems concerning palliative care research in LMIC, such as the absence of national strategies,[18] isolation,[18] and dominance of the biomedical model.[2] Biomedical dominance is especially problematic in LMIC, where there are fundamentally different philosophical approaches to health, healing, illness, death, body, and other concepts that have been studied for years in medical anthropology.[55] The rigid methods currently postulated by the scientific community reach their limits in view of these divergent contexts. Furthermore, there are other sources of bias such as literary deficiencies.[47]

Shifting the Imbalance

Although the need to increase skills and capacity of research in LMIC is undisputed, the clinical provision of care is considered to have higher priority than the development of research capacity. Scholars from LMIC should be able to carry out excellent quality research in their own country, e.g., through the integration of research methods into their existing curricula.[47] This includes learning under the specific local conditions, as well as recognizing the influence of cultural factors on clinical symptoms and treatment outcomes. However, without guidance and encouragement from those with research expertise and resources, such training programs may be fruitless.

Collaborative research[56] between HIC and LMIC,[47] motivated by common scientific interest, historical relations, language, and other interests, should stay away from a “semicolonial model”[57] and “tropical medicine.”[32] Furthermore, this collaboration should address inequity and be relevant to the population in which research projects are carried out, putting local priorities first.[58,59] There must be a “true commitment to listening to local voices” to understand local problems,[60] respecting values and choices. Other key aspects are sustainability and the development of national research capacities with a longer term perspective.[57,58]

Creating a network of researchers between different LMIC may be an efficient strategy to improve collaboration.[61] Likewise, collaborative research between clinicians and social scientists may also be important for stimulation of the multidimensionality of palliative care research.[62]

International journals must be active partners. Scientific journals play a crucial role in promoting research from LMIC. For example, high-impact journals with international reputations could advocate for international palliative care research or for increasing the regional representation of editorial boards and the assignment of special reviewers to papers submitted from LMIC.

Last, funders should finance monitoring and evaluation, helping to ensure effective and systematic documentation and replication of studies and creating a culture of research.[47]

Conclusions

The visible increase in palliative care research and publications in the world shows a growing participation of LMIC (especially UMC). However, research studies from a major part of the global population are still underrepresented.

Understanding and discussing the reasons for underrepresentation of LMIC in the international scenario may be the beginning of a resolution of the vicious circle affecting universal scientific knowledge. New strategies should be developed to resolve this vicious circle in which poor production of scientific knowledge results from and contributes to limited support for research.

Motivation to carry out research and publish results should be increased through awareness about the importance of research and its promulgation regarding the identification of needs, the allocation of resources, and the implementation of evidence-based measures with the consequent health improvement. Furthermore, the conditions of development of research should be supported by adequate training, disposition of time and resources, acknowledgment of research work, and the publishing of results by international journals. This means that not only health care providers but also decision makers in the local health care systems as well as funders would have to develop a culture of research.

In sum, palliative care research from developing countries is essential to develop and implement practices and to monitor the quality, efficacy, and efficiency of the delivery of palliative care appropriate to resource-poor settings, as well as to identify the needs of specific local populations.[19,63]

The development of appropriate practices in palliative care in LMIC requires research, and hence, resources, as well as engagement from international journals; partnership collaboration from HIC; and tailored funding to support researchers, collaborations, and networks.

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