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Title: International palliative care research in the context of global development: a systematic mapping review

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Global Palliative Care, International Research, Systematic Mapping Review, International Development

International palliative care research in the context of global development: a systematic mapping review

ABSTRACT

Context: An increasing amount of health policy is formulated at global level. At this global level, palliative care has attracted support primarily from normative institutions (World Health Organization), not funding agencies. To attract greater global attention from policymakers, it has been argued that an international approach to research is required. However, the extent to which an international approach is being undertaken is unknown.

Objectives: To systematically identify and thematically synthesise all international palliative care research, defined as research involving two or more countries, or focussed upon the global level.

Methods: Five bibliographic databases (CINAHL, Cochrane Library, ASSIA, Web of Knowledge, Psychinfo) were searched for journal articles relevant to international and global palliative care and end of life care. Data were extracted using a piloted extraction form and findings were synthesised.

Results: 184 studies were included, published across 75 different academic journals. Research emanates from and focusses upon all world regions and there is increasing focus upon the global level. Thematically, there is a high focus upon Evaluation (n=53) and views of Stakeholders (n=38). The review revealed a predominantly observational research approach and few interventional studies were identified.

Conclusion: International palliative care research is a relatively new, but growing field. However, many gaps in the evidence base remain and palliative care research continues to take place outside broader discourses of international development. The relative absence of interventional research demonstrating the effectiveness and cost-effectiveness of palliative care, risks limiting the tools with which advocates can engage with international policymakers on this topic.

INTRODUCTION

The world has a growing and ageing population. Older people are the demographic with the highest health system usage and there is a growing imbalance of people of working age in relation to dependents and a consequent reduction in people contributing to health systems funding.[1] Additionally, an almost two-fold increase in the number of people dying globally is predicted over the next 40 years, with people expected to experience more complex and costly health and social care problems as they approach the end of their lives.[2] This challenges both the capacity and sustainability of health systems. Further roll out of palliative care services internationally has until recently received little global-level attention is spite of ‘global ageing’ emerging as a key area for international development.

It is suggested that increased access to palliative services holds the potential for wide ranging benefits for patients, families and health systems.[3] These include reduced overall health expenditure through reduced usage of primary and critical care, reduced out-of-pocket expenditure for households as well as a reduction in human suffering, through appropriate care. Conceptualising palliative care in economic terms as well an urgent health need, allows it’s consideration as an international development issue which aims to increase levels of both human and economic development.[4]

Advocates argue that as up to 80 million people who would benefit from palliative care each year do not receive it, a public health approach to further development is required.[5] Most of this unmet need is in low-income countries, where the need for palliative care is particularly acute, as illnesses such as cancer are typically diagnosed at a late stage when curative efforts may not be either effective or appropriate. As such, in 2007 it was argued that a global approach to the development of the field of palliative care is required in terms of leadership, knowledge sharing and advocacy.[6] Such an approach needs to be seen in the context of the challenges and opportunities presented by the globalization of health care which has seen an increase in health policy formulated at global level.[7] Indeed, although palliative services now exist in 136 of the worlds' 234 countries[8], services remain concentrated in high-income countries. Whilst other health issues such as HIV/AIDS have gained global attention and consequentially, high levels of funding[9], palliative care has developed only patchily, often as a result of civil-society action, rather than following global or national leadership.

At the global level, the current response from global organizations such as the United Nations (UN) and the World Health Organization (WHO) to the 'problem' of global ageing has centred around the promotion of 'active and healthy' ageing. For instance, the WHO's Framework for Active Ageing aims to increase wellbeing in older people as well as reduction in health systems costs through decreased usage.[10] However, in spite of many studies demonstrating a link between illness, death and household poverty[11], little global attention has been given to how the negative effects of terminal illness and bereavement may be reduced through appropriate intervention. Indeed, with reports that emotional bereavement is a luxury which many in lower-income countries cannot afford,[12] attention to the financial aspects of illness and bereavement appears warranted and may allow palliative care to be presented to policymakers as part of broader efforts towards poverty reduction.[4]

Yet, there are signs that palliative care has been receiving increasing attention from global policymakers. In 2014, for instance, the World Health Assembly passed a Resolution which called for palliative care to be further rolled out as part of health systems strengthening.[13] Additionally, international civil society organizations make the argument that that failure to provide access to palliative care represents a breach of human rights[14]. Furthermore, palliative care has been acknowledged within the new global policy priorities, the Sustainable Development Goals (SDGs) as part of Universal Health Coverage (UHC).[15] However, it is of serious concern to the field that no goal or indicator has been included to measure palliative care development within the SDGs, leaving palliative care in an ongoing struggle for attention from national and global policymakers.

It is known that in order for health issues to attract the attention of policymakers, an evidence-base is required.[16] Often provided through international research networks, evidence of effectiveness and cost-effectiveness of interventions can equip advocates with the tools required in order to influence policy-decisions and resource allocation. Additionally, backed by evidence, advocates are able to engage with the less tangible issues of policy prioritisation such as how health problems should be 'framed' to resonate with global policymakers.[7]

However, there are ongoing concerns regarding the evidence-base that palliative care researchers are providing to policymakers.[17] For example, there are issues relating to the difficulties of measuring outcomes in palliative care such as; quality of care, quality of death and bereavement resolutions. In addition, research capacity is low, particularly in low-income regions like Sub-Saharan Africa, where there are concerns that research lacks the resources to inform the delivery of appropriate care.[18] Further, there are various barriers to the production of high-quality research, such as, ethical issues associated with conducting research on vulnerable populations.[17]

As research capacity in low and middle-income countries is low, it is important for researchers in other settings, to produce evidence which has international relevance.[19] For instance, given suggestions that palliative care services such as that in Kerala may be transferrable to other settings, the extent to which evidence supports such claims, is unknown.[20] In recognition of the need for internationally relevant evidence, initiatives such as the European Palliative Care Research Collaborative [EPCRC] have emerged to facilitate the implementation of European evidence based guidelines in palliative care.[21] However, with an urgent need for research collaboration between low and high-resource countries[22], the extent to which western researchers in palliative care are supplementing research evidence in other settings is unknown. Moreover, no study has yet, to date, sought to understand and categorise the landscape of international palliative care research to determine whether research capacity in under-researched regions is being supplemented by international researchers.

Given these gaps in our understanding, the aim of this study was to conduct a systematic mapping review to identify all published literature on international palliative care research. We defined 'international research' as involving two or more countries due to the potential of comparative research to increase common understanding.[23] In the same regard, studies focussed on the 'global' level were included as well as papers from a single country if they specifically and primarily focussed on the international transferability of their findings. This approach was adopted to achieve the aim of producing a thematic map of international research themes and issues. Additionally, we examined the extent to which attention is focussed upon low-income countries where little palliative care research is known to be conducted by national researchers. Finally, our analysis asked whether the evidence-base being produced by international researchers facilitates consideration of palliative care as a public health issue and/or a concern for the broader international development community. This review is the first of its kind to examine the quantity and scope of international palliative care research

METHODS

A systematic mapping review is an established method of literature review employed in order to map out and categorize existing literature from which to commission primary research by identifying gaps in the research literature'. [24] This method is appropriate for reviews which anticipate large numbers of included studies. This review method was selected as opposed to other methods which combine heterogeneous literature, such as narrative review, due to ongoing association between narrative reviews and a lack of systematic approach.[25]

Data sources and study selection

Following a scoping exercise of keyword search terms, a search strategy using MeSH headings and keywords was formulated [Table 1] and agreed with an Information Specialist and experts in the fields of palliative care and international health policy research. Scoping also involved the removal of unnecessary search terms that mapped to existing terms, to streamline the search process. The strategy was designed to be as sensitive and systematic as possible. Inclusion/exclusion criteria were devised which could identify papers that may answer the research questions appropriately [Table 2].

Five bibliographic databases (CINAHL, ASSIA, Web of Knowledge, Cochrane Library and Psychinfo) were searched using the developed search strategy. Searches were conducted between the 4th and 9th of July 2013, no start date filter was applied. Hand searching of reference lists and experts in the field were consulted to identify additional relevant texts.

Table 1. Summary of search strategy

1. Global OR International OR Europe OR Africa OR Asia OR North America OR South America OR Transnational OR World OR Universal OR Supranational OR Multinational OR “Developing Countries”

AND

2. Palliat OR Hospice OR “Opioid availability” OR “Supportive Care” OR “Terminal illness” OR “Terminally ill” OR “Terminal disease” OR “End-of-life” OR “Terminal Care” OR “Care of the dying” OR bereavement

3. 1 AND 2

The electronic search strategy yielded 14058 outputs which were imported into Endnote along with one additional paper identified through discussion with experts in the field (n=14059). Duplicates (n=1894), books and book chapters (n=499), patents (n=22) and theses (n=31) were removed. The remaining outputs (n=11613) were then exported to Microsoft Excel for the inclusion/exclusion criteria to be applied [Table 2].

Table 2. Inclusion / Exclusion Criteria

Included**;**

To be included, outputs had to be;

- ‘International research’ defined as research focussing upon two or more countries, the global level, or national research which explicitly focusses upon international transferability of findings
- Empirical research published in full with methods reported
- Relevant to palliative care, palliative medicine or end-of-life-care

- Available in full text form
- Available in English
- Published in a peer-reviewed journal

Excluded**;**

Outputs were excluded if they were;

- Outputs where search terms are used out of context
- Conference proceedings
- Book chapters/book reviews
- Non-empirical papers (methods not reported) e.g. non-systematic reviews
- Editorials/Commentaries/Opinion Pieces/Letters/Theses/News articles/Policy statements/Grey literature

A total of 11613 articles were initially reviewed by JC using title/abstract, of which 11123 articles did not meet the inclusion criteria. Full text articles were then retrieved for the remaining 490 papers and the inclusion/exclusion was applied by JC. Following this, a second independent screening of all included titles/abstracts was undertaken by CG and consensus agreed by discussion in cases of disagreement. The full process of study identification is presented in the flow diagram [Fig. 1].

Fig. 1. Identification of relevant studies

Decisions regarding the quality of research were made by reviewing study designs as per the hierarchy of evidence.[26] This approach was used with caution, recognising that different study designs are appropriate for answering different questions and that randomised controlled trials, the ‘gold standard’ in research, are not feasible in all scenarios. This is especially true in in palliative care research, where ethical issues surrounding randomisation and the inclusion of vulnerable groups in research limit the occasions where such trials are appropriate.[27] Nevertheless, as global health policymaking continues to become more evidence-based,[28] it was deemed appropriate to consider the type and strength of study designs being used in international palliative care research.

Data Extraction

A total of 184 studies met the study inclusion criteria [Appendix 1]. Each included study is referred to as an output.

Data were extracted from all outputs using a data extraction form, which had been piloted to ensure that all relevant data were captured. The outcomes extracted are reported in Table 3.

Table 3. Outcomes Extracted from Included Studies

1. Year of publication
2. Journal of publication
3. Region(s) of output focus
4. Country of First Author of output
5. Thematic focus of output
6. Study design

- Eg; cross-sectional, randomised controlled trial etc.

Data analysis was conducted using a descriptive thematic method for data synthesis[29]. This method was chosen as it facilitated the aim of the review: to systematically produce an overview of international palliative care research based on the thematic focus of included papers.

The development of thematic categories was undertaken using a two-phased approach. Firstly, a 'descriptive coding' method was used to identify the primary focus of outputs based upon abstracts and full texts.[30] Secondly, mind-maps were used in order to examine relationships between emergent codes which resulted in the development of overarching themes which were then checked by a second author (CG). Themes therefore emerged from the coded outputs themselves and it follows, that many outputs were potentially relevant to more than one theme. When such issues occurred, they were resolved by discussion amongst the study team and outputs were allocated to themes with an emphasis upon the primary research objectives of each study as opposed to being guided by the title of the work. Findings were then summarised descriptively.Data extraction originally intended to extract data which specified each country involved in the research, however, this information was commonly not reported e.g. studies referred to participants from 'several European countries', rather than reporting each country by name. Therefore, data was extracted by region rather than by country. Country-level information was extracted if it was noted, to enrich analysis and discussion.

Regions were characterised along continental lines, with the 'non-continental' Caribbean grouped with South America. Papers which solely focussed upon the global level rather than a particular region were described as 'global'. The term 'global' is used where worldwide relevance is suggested, whereas 'international' is used to refer to more than one country.

RESULTS

Total outputs by year of publication

The earliest research paper identified on palliative care in an international context was published in 1986 (n=1) [Fig. 2]. Between 1986 and 1990, only one more paper was published, indicating that the development of international palliative care research remained slow during that period.

The following ten years up until 2000 showed increased outputs in the field of international palliative care with 16 papers published across this decade. Since then, there has been an exponential rise in international research activity in the field, with 151 relevant papers published between 2001 and 2012.

Fig. 2. Total outputs (n=184) by year of publication (n=23)

The increase in research output from 2006 follows the publication of at least 2 WHO policy papers in 2004 calling for palliative care to be an international public health policy.[531] Additionally, the Journal of Pain and Symptom Management (JPSM) published a special issue on international palliative care in 2007, many papers from this issue are included in the review which helps explain the spike in output of that year.

From the end of 2012 up until July 2013, when the searches were conducted, 15 relevant papers had been published.

Journal of Publication

The 184 included outputs were published in 75 different peer reviewed journals. Of these, only 23 journals have published 10 or more outputs [Table 4], with the Journal of Pain and Symptom Management and Palliative Medicine publishing the greatest proportion of articles (n=39 (21%) and n=24 (13%) respectively).

Table 4. Top 6 Journals which have published included international palliative care research articles

Journal title	Total
Journal of Pain and Symptom Management	39
Palliative Medicine	24
Journal of Palliative Medicine	10
Journal of Palliative Care	7
BMC Palliative Care	5
International Journal of Palliative Nursing	5

Other outputs were located in a wide range of journals varying from BMC Public Health (n=3) and Social Science in Medicine (n=2), to the Journal of Aids and Behaviour (n=1). The range of journals represented a wide range of disciplines, including medicine, nursing, social work and others.

Location of First Author

The location of the first author was extracted by noting the country in which the lead authors' institution was located [Fig.3]. There was an uneven distribution in the geographical location of first authors who have published palliative care research in an international context.

Fig 3. Location of first author based on home institution

Using the country of the first authors' organization as an indicator reveals that 55% of international research originated from Europe, 23% from North America, followed by Asia, with 12%. The lowest levels of international research activity were found in Australasia (5%), South America and the Caribbean (3%) and Africa with only 2% of first authors based in this region.

Region of research focus

The focus of the research by region was extracted by noting the regions in which the actual research took place and/or the study was concentrated, as opposed to the location of the first author. In terms of the region of research focus, Europe was the most researched region, with 32% of international research focussed there [Fig. 4]. Following hits, there is a relatively even spread between regions. The Global level was the second most researched areas with 15% of international focussed on region, followed by Asia (13%) and North America (13%), Africa (11%) and Australasia (10%) well represented. South America and the Caribbean receives the least research focus (7%) however, the region is more prominent than suggested by the location of first authors.

Fig 4. Focus of included outputs by region (n=7)

The disparities between region of first author and research suggest that research focussed on these regions is not actually being led by those who are based in or *from* these regions. For example, a study where the first (and contact) author is based in the United States explores palliative care for persons with HIV/AIDS in Africa.[32] Additionally, one UK study moves beyond contributing to the evidence-base in a developing setting (Uganda) and aims to increase the research capacity of local researchers.[33]

Moreover therefore, these results suggest that there is greater research funding and capacity in developed regions (such as Europe and North America) which enables researchers to conduct research in an international context.

Thematic analysis and quality of evidence

Through descriptive analysis of included outputs, a total of 10 thematic groups emerged which are reported and described in Table 5.

Table 5. Overview of thematic categories (n=10)

Theme	Total studies within theme (n=184)	Description
Death and dying	13	Outputs focussing upon issues relating to death and dying – including assisted dying – from a palliative care perspective. .
Education	12	Outputs focussed upon palliative care teaching, training, education and curricula.
Ethics	3	Outputs examining ethical issues relevant to palliative care, such as; decision-making, research practice and attitudes.
Evaluation	53	Outputs conducted performing evaluations of palliative care interventions; including service models, models of clinical practice, pharmaceutical interventions, clinical tools, patient

		outcome measurement tools etc.
Law	1	Outputs reporting legal issues and legislation in palliative care, either specific to palliative care or generic legislation that is relevant to aspects of palliative care.
Methodological	2	Outputs reporting on issues relating to methodology in palliative care research, including methodological challenges and opportunities in palliative care research.
Policy	27	Outputs reporting policy-level issues relevant to; standards, opioid availability, human rights, consensus building and international organization guidance etc.
Services and Settings	28	Outputs reporting different palliative care services around the world in terms of models and foci of care (eg home care / disease specific care) as well as settings (eg rural areas). Typically included outputs focussed upon the identification of services and did not conduct full evaluation.
Stakeholders	38	Outputs reporting on issues specific to different stakeholders in palliative care eg. physicians, nurses, patients, families etc. Commonly, included outputs focussed upon the 'attitudes' of these groups to specific issues.
Symptom Management	7	Outputs reporting on symptoms of palliative care patients (eg. Cancer pain), symptom prevalence and management.

Of the 184 empirical research papers included in the review, Evaluation (n=53, 29%) was the dominant theme [Table 5]. Many studies within this theme focussed upon tool-validation. For example, one study evaluated the palliative care assessment tool - the Sheffield Profile for Assessment and Referral for Care (SPARC).[34] This tool was developed in one context (United Kingdom) and was then evaluated in another (Poland). Also common, were evaluations of different models of care. Such studies tended to focus upon one specific model of care and then make extrapolations of how a similar approach may work in other contexts and regions.[35]

Stakeholders was the second most prevalent theme (n=38) with 21 % of the research focus. Within this theme, many studies used questionnaires to elicit the attitudes, practices and experiences relevant to end of life care from different groups such as; physicians,[36] nurses,[37] patients,[38] and the general public.[39]

The third most researched theme, with 15% of the research focus, Services and Settings (n=28). Studies within this theme focus primarily upon efforts to map the existence of availability of palliative services internationally.[40] Additionally, specific services within broader palliative care are reviewed including; deep sedation[41] GP home visits[42] and bereavement support.[43]

Also with 15% of the research focus, was Policy (n=27). Many studies within this theme focussed upon issues such as access to essential medicines,[44] consensus-building,[45] barriers to the development of palliative care[46] as well as articulations of clinical standards in palliative care.[47]

Relatively low engagement with issues relating to death and dying (n=13, 7%) are revealed by the review. There is also a low level of research focussed upon efforts to improve Education within palliative care (n=12, 7%) and Symptom Management represents only 4% of international research output (n=7). Finally, there is low engagement from international researchers with ethical (n=3, 2%) and methodological (n=2, 1%) issues relating to palliative care and only 1 paper focussed on legal issues in international context.

Study design and quality of evidence

In terms of research methods, of the 184 empirical articles included, 88 (50%) were produced using quantitative methods, 37 (21%), qualitative methods and 31 (18%) were mixed-methods papers, and 20 (11%) were systematic reviews.

Looking more closely at the study design of primary approaches and the quality of evidence being produced, this review reveals that the growing evidence-base for palliative care in an international context consists largely of study designs which are low on the hierarchy of evidence.[26] The most prevalent study design was cross-sectional studies with 92 outputs using this method, of which 22 had a retrospective direction. Systematic reviews (n=23) were the second most prominent study design, followed by Cohort studies (n=8). Just two randomised controlled trials (RCTs) were identified[4849] and only one economic evaluation.[50]

Whilst it has been recognised that the hierarchy of evidence is a relatively crude measure of quality appraisal, the high prevalence of descriptive, rather than interventional, studies remains a concern. There is also an absence of longitudinal studies, suggesting an absence of research on how relevant outcomes change over time.

DISCUSSION

This review reveals that the field of international palliative care research is a relatively new but growing field, with some international research activity in all regions of the world.

Research is however, predominantly focused in Europe and North America. This echoes findings from a 2004 study which found a low level of geriatric palliative care research emanating from low and middle-income countries and suggested an association between the level of palliative development within a region and its research output.[65] This is perhaps unsurprising and reflects broader trends in academic research in developed regions where greater funding and institutional capacity exists that facilitates greater research output.[51] More pertinently, publications focussing upon the global level indicate that there is growing engagement with palliative care as a global issue. Findings suggest that, to some extent, researchers from high-income regions, such as Europe and North America, are undertaking research in low and middle-income regions of the world, such as Africa. However, some opportunities do appear to being missed by researchers regarding the production of evidence which may assist policymakers seeking to implement the terms of the WHA Resolution and ensure palliative care is included as part of the new global priorities to achieve Universal Health Coverage (UHC). The conclusion therefore considers some of the key issues arising from the review as well as potential strategies for researchers to progress palliative care as an important global health issue.

International research; networks and challenges

There are signs that international research networks are emerging, with researchers from different countries working collaboratively, through research projects such as the EURELD Consortium commissioned by the European Union.[52] This is significant due to the potential held by international research networks to exert influence within policymaking processes.[7]

For instance, EURELD conducted a study of physicians' attitudes towards end-of-life decisions comparatively between seven countries. Such studies serve to identify the acceptability of different policies and practices across countries as well as helping to forge consensus with regards to ‘best practice’ in palliative care.[53] International research projects such as EURELD deliver synthesised findings directly to policymakers increasing the likelihood of policy influence and may encourage a movement towards the development of internationally recognised standards in palliative care.

The internationalisation of research does, however, potentially raise new issues for researchers in palliative care and particularly for those from richer countries who are conducting studies in poorer regions. Challenges are multi-faceted and include a range of ethical issues such as: ensuring the relevance of research to local populations, conducting research to international ethical standards regardless of national regulations and involving local people and researchers to ensure that research is participatory, with informed consent.[54] There are also broader questions regarding the legitimacy of researchers from richer nations conducting research in lower-income settings, given the uneven power relations that inevitably exist in such research contexts [55] and the risks of imposing western norms in differing cultural contexts.[56] Such issues can be considered *additional* to barriers which exist to palliative care research at national-level such as the (extreme) view that palliative care patients should not be asked to participate in research at all[57] and the legal and ethical difficulties regarding whether a surrogate can or should provide consent for subjects who lack decision-making capacity.[58]

In light of the low quality of evidence identified by this review, it is of concern that only one paper emerged which engages with methodological issues. There is an additional absence of research which engages with how barriers to conducting ethically sound research can be overcome in order to improve the quality of the evidence base. Nor are there any examples of methodological learning from other research disciplines which focus upon vulnerable populations that may face similar challenges to the production of evidence.

Palliative care is a discipline which has historically faced problems conducting study designs like RCTs due to the ethical complications inherent when randomising patients. Whilst the absence of palliative care services in many countries of the world is of great concern, this circumstance may offer opportunities for researchers to cast light on the true scale of human suffering caused by lack of access to palliative services. For instance, comparative evaluative research may be justifiable, examining difference in patient, family, and health systems outcomes, between nations or regions where there are palliative services and those where there are none. This may be conducted with no study intervention and could be conducted alongside capacity-building efforts to empower researchers in settings where little or no research is currently taking place. The absence of services is a grave omission from such countries' health systems. However, pragmatic evaluative research of this manner, may help draw attention to the very real suffering which occurs in such settings and also provides an opportunity to evaluate the effectiveness and cost-effectiveness of palliative care.

Researchers may also consider looking beyond the field, at other disciplines which have faced similar barriers to high quality research. The Global Network for Women's and Children's Health Research (CNWCHR), for instance, has successfully overcome ethical and regulatory challenges to conduct trials involving pre-term babies and produce a robust evidence base. [59] Currently it seems that the international approach adopted by palliative care researchers extends only within the field and not more broadly to examine how other disciplines have been able to overcome the barriers to ethically conducted international research on vulnerable groups.

Global Ageing and International Development

No outputs were published in journals which focus specifically on international issues relating to development or ageing more broadly, which suggests that research is conducted *within* the field and that palliative care has not yet attracted the attention of the broader global health research community. Additionally, no studies engage with the major health financiers, such as the World Bank, as existing or potential future funders of palliative care. This suggests that international palliative care continues to operate outside of broader discourses of international development, global ageing and global health. This is of major concern, as in a global policy context where above all, poverty reduction is prioritised, it seems palliative care researchers are missing opportunities to make a case for a how a holistic intervention pre and post bereavement may be able to reduce avoidable suffering whilst contributing to broader development priorities.

In this regard, the lack of interventional research and evidence of the economic viability of palliative care services is of further concern. Global funding agencies such as the World Bank characterise global health in economic terms and are influenced by economic evidence in making their funding decisions.[60] Moreover, such agencies will disburse funding towards the achievement of UHC using 'results-based financing.'[61] In this regard, ongoing problems regarding how to define the inputs and outcomes of palliative care services to determine both their feasibility and effectiveness, makes it likely that palliative care will not benefit from funding allocated in this manner. Lastly, development appears to have accelerated in countries such as Costa Rica and Australia which have incorporated palliative care as part of universal health coverage.[62] It therefore seems a major omission, that no studies were identified which evaluated such models with consideration of their transferability to other settings. In order to appeal to key global funding agencies, future research needs to resonate more directly with international development discourses. For instance, it may seek to explore the links between illness and poverty and how palliative care may be an appropriate intervention at the end of life to help mitigate negative financial aspects of death relating to household poverty. National level research has demonstrated how palliative care can help reduce costs to families and health systems of treating patients at the end of life.[63] The argument that palliative care is both an appropriate form of care as well as being the cheapest is convincing. Moreover, presented in this manner, a strong argument can be made for palliative care to a broader international development audience. Once more, researchers may profit from looking outside the field, to see how health lobbies like the HIV/AIDS movement gained global attention, by presenting HIV/AIDS as both a humanitarian crisis and a limiter of economic growth through reduction of human capital due to AIDs-related deaths.[64]

Public Health

A total of 11 studies were identified which explicitly took a public health perspective. Three of these studies evaluate existing services and provide evidence in support of a public health approach to palliative care delivery. Other studies focus largely upon access to essential medicines and on ‘place of death’ as an outcome. However, no studies provide comparative evidence of effectiveness or cost-effectiveness of palliative care for health systems, households or individuals. Global ageing policies continue to further the argument for ‘healthy ageing’,[10] however, this negates the truism, that no matter how healthily populations age, death can only ever be postponed and health systems must be robust enough to meet this challenge. Therefore, the absence of research which places palliative care within the context of broader health systems strengthening is a concern.

There is also a substantial shortage of interventional research and evaluation of palliative care delivery within the broader context of health systems in terms of, feasibility, effectiveness and cost-effectiveness. This finding broadly mirrors the findings of a review of worldwide survey geriatric palliative medicine which also identified a shortage of experimental studies.[65] The low prevalence of RCTs suggests that questions remain regarding the appropriateness of this methodology in palliative care research[66] in spite of increasing evidence that cluster randomisation can be an effective design for research in end of life situations.[67]

The opportunities for further funding and development provided by the WHA Resolution in 2014 and the Sustainable Development Goals must not be left to pass. Further international research is required to educate and engage the public and policymakers regarding what palliative care can offer and to demonstrate its effectiveness. Increased understanding and evidence of the broad range of benefits palliative care can give to individuals, health systems and societies is still needed in order to engage the international development community. A new research agenda which places palliative care within broader global health discourses as an economically viable and essential part of Universal Health Coverage may be fruitful.

LIMITATIONS

As all relevant papers identified by the study identification process were included, the risk of bias within the review is deemed low. One limitation of the study was *language bias* as only English language studies were searched for and included. However, no studies were specifically excluded based on language by the authors.

There is a small amount of bias away from clinical aspects of palliative care in favour of palliative care more as a policy issue. For instance, clinical trials which have relevance for palliative care and are likely to have benefits for many patients may not have been identified due to using the blanket term ‘opioid’ to identify issues relating to essential medicines and non-inclusion of specific palliative treatments in the search strategy.

This approach is line with the aims of the study to consider international palliative care research, rather than studies which *may* have international relevance. There is no implication that clinical outcomes from drug treatments are likely to differ amongst similar patient groups, however, the international relevance of studies would have had to be made explicit in either title or abstract for the study to have been identified by the search strategy. On this basis, it must be acknowledged, that in spite of a rigorous search strategy, some relevant papers may not have not been included in the review.

CONCLUSION

This review has demonstrated that trends in national-level palliative care research are being continued in an international context. Most international palliative care research is conducted in high-income settings. However, it has been shown that an increasing amount of palliative care research is taking an international approach and that researchers are looking beyond their national contexts to conduct research in other world regions.

Nevertheless, in spite of a global need for innovative policies to address issues relating to global ageing, the contribution of emerging research networks appears to be occurring outside broader development discourses. National-level research demonstrating reduced costs to health care systems is not currently being ‘framed’ as a rationale for further roll-out of services to global policymakers. Nor is research being presented within broader global health and development discourses. Amidst competing global claims for limited resources, the ongoing emphasis upon palliative care as an area of need, without considering how it relates to other global health issues warrants reconsideration. Researchers should consider a pragmatic, hard-nosed approach to research which focuses on the economic potential of palliative care services which would appeal to international development funders. Should this lead to a further roll-out of palliative services, a reduction in individual and family suffering relating to illness and death would surely follow.

Funding

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Competing interests

None declared

Ethics

Ethical approval for the review was received as part of a broader PhD project, from the ScHARR Research Ethics Committee, University of Sheffield.

Contributors

JC was responsible for study design, management of the project, systematic searching and data extraction, analysis, and drafting of the manuscript. CG was responsible for study design, application of inclusion/exclusion, data extraction and manuscript review. AB was responsible for theoretical input and manuscript review. All authors approved the final manuscript.

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Fig 2. Total outputs (n=184) by year of publication (n=23)

Fig 3. Location of first author based on home institution

Fig 4. Focus of included outputs by region (n=7)

REFERENCES

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[1] HelpAge International. Ageing in the 21st Century: Ten priority actions to maximise the opportunity of ageing populations. 2015. Available from: http://www.helpage.org/resources/ageing-in-the-21st-century-a-celebration-and-a-challenge/ageing-in-the-21st-century-ten-priority-actions-to-maximise-the-opportunity-of-ageing-populations/. Accessed 15 April. 2015.

[2] Gomes B, Cohen J, Deliens L, et al. International trends in circumstances of death and dying. In: Gott M and Ingleton C (eds) Living with ageing and dying: palliative and end of life care for older people. Oxford: Oxford University Press, 2011, pp. 3–18.

[3] World Health Organization. WHO Definition of Palliative Care. 2015. Available from: http://www.who.int/cancer/palliative/definition/en. Accessed 06 June, 2015.

[4] Ranis G. Human Development and Economic Growth. 2004. Available from: http://www.econ.yale.edu/growth_pdf/cdp887.pdf. Accessed 03 July, 2015.

[5] World Health Organization. Palliative care for older people: better practices. 2004. Available from: http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf. Accessed October 01, 2014.

[6] De Lima L, Doyle D. The International Association for Hospice and Palliative Care list of essential medicines for palliative care. J Pain Palliat Care Pharmacother 2007;21(3):29-36.

[7] Deacon B. Global Social Policy and Governance. London: SAGE Publications, 2007.

[8] Worldwide Palliative Care Alliance. Mapping levels of palliative care development a global update – 2011. Available from: http://www.thewhpca.org/resources/item/mapping-levels-of-palliative-care-development-a-global-update-2011. Accessed June 22, 2015.

[9] UNAIDS. Financing the Response to HIV in low-and Middle-Income Countries: International Assistance from Donor Governments in 2012. 2014. Available from: http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/document/2013/09/20130923_KFF_UNAIDS_Financing.pdf. Accessed 07 July, 2015.

[10] World Health Organization. Active Ageing: A Policy Framework. 2002. Available from: http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH_02.8.pdf?ua=1. Accessed 15 April, 2015.

[11] Russell S. The Economic Burden of Illness for Households in Developing Countries: A Review of Studies Focusing on Malaria, Tuberculosis, and Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome. Available from: http://www.ncbi.nlm.nih.gov/books/NBK3768/?report=printable. Accessed 06 June, 2015.

[12] Demmer, C. and G. Burghart (2008). "Experiences of AIDS-related bereavement in the USA and South Africa: a comparative study." International Social Work 51(3): 360-370.

[13] World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course. Available from: http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf. Accessed 07 July, 2015.

[14] Jackson K. Palliative care and international human rights law. Available from: http://www.ehospice.com/Default/tabid/10686/ArticleId/13335. Accessed June 19, 2015.

[15] United Nations. Sustainable Development Goals. Available from: https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals. Accessed July 07, 2015.

[16] Birbeck GL, Wiysonge CS, Mills EJ, et al. Global health: the importance of evidence-based medicine. BMC Medicine, 2013;11(223)1-9.

[17] Higginson I. Evidence based palliative care. BMJ 1999;319:462-464.

[18] Harding R, Powell RA, Downing J, et al. Generating an African palliative care evidence base: The context, need, challenges and strategies. J Pain Symptom Manage 2008;36(3):304-309.

---

[19] Pastrana T, Vallath N, Mastrojohn J, et al. Disparities in the contribution of low- and middle-income countries to palliative care research. J Pain Symptom Manage 2010;39(1):54-68.

[20] Bollini P, Venkateswaran C, Sureshkumar K. Palliative care in Kerala, India: A model for resource-poor settings. Onkologie 2004;27(2):138-142.

[21] European Association for Palliative Care. Form for EAPC web platform about EU supported projects. 2004. Available from: http://www.eapcnet.eu/LinkClick.aspx?fileticket=u_1-G8ghS30%3D&tabid=632. Accessed January 10, 2016.

[22] Akinremi TO. Research collaboration with low resource countries: overcoming the challenges. Infect Agent Cancer, 2011;6(2):S3.

[23] González Block MA. Comparative research analysis methods for shared learning from health systems reform. Health Policy, 1997;42(3):187-209.

[24] Grant MJ, Booth A. A Typology of reviews: an analysis of 14 review types and associated methodologies. Health Info Libr J 2009;26:91-108.

[25] Usam LS. Systematic Reviews and Meta-Analyses. J Can Acad Child Adolesc Psychiatry, 2001;20(1):57-59.

[26] Evans D. Hierachy of evidence: a framework for ranking evidence evaluating healthcare interventions. JCN 2003;12:77-84.

[27] Fowell A, Russell I, Johnstone R, Finlay I, Russell D. Cluster randomisation or randomised consent as an appropriate methodology for trials in palliative care: a feasibility study. BMC Palliative Care 2004;3(1)

[28] Yamey G, Feachem R. Evidence-based policymaking in global health – the payoffs and pitfalls. JEBM 2011;16(4);97-99.

[29] Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med res Methodol 2008;8(45).

[30] Saladna J. The Coding Manual for Qualitative Researchers. 2009. London: SAGE Publications.

[31] World Health Organization. Palliative care: the solid facts. Available from: http://www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf. Accessed October 01, 2014.

[32] Alexander CS, Memiah P, Henley YB, et al. Palliative Care and Support for Persons with HIV/AIDS in 7 African Countries: Implementation Experience and Future Priorities. American J. Of Hospice And Palliat. Medicine 2012;29(4):279-285.

[33] Marshall-Lucette, S., K. Corbett, et al. (2007). Developing locally based research capacity in Uganda. International Nursing Rev, 2007;54(3): 227-233.

[34] Leppert W, Majkowicz M, Ahmedzai S. The adaptation of the Sheffield Profile for Assessment and Referral for Care (SPARC) to the Polish clinical setting for needs assessment of advanced cancer patients. J Pain Symptom Manage 2012;44(6):916-922.

[35] Herrera E, Rocafort J, De Lima L, Bruera E, Garcia-Pena F, Fernandez-Vara G. Regional palliative care program in Extremadura: An effective public health model in a sparsely populated region. J Pain Symptom Manage 2007;33(5):591-598.

[36] Bruera E, Neumann CM, Mazzocato C, Stiefel F, Sala R. Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. Palliat Med 2000;14(4):287-298.

[37] Coenen A, Doorenbos AZ, Wilson SA. Nursing interventions to promote dignified dying in four countries. Oncol Nurs Forum 2007;34(6)1151-1156.

[38] Ando M, Morita T, Ahn SH, Marquez-Wong, F, Ide S. International comparison study on the primary concerns of terminally ill cancer patients in short-term life review interviews among Japanese, Koreans, and Americans. Palliat Support Care 2009;7(3):349-355.

[39] Bausewain C, Calanzani N, Daveson BA, et al. 'Burden to others' as a public concern in advanced cancer: a comparative survey in seven European countries. BMC Cancer 2013;13.

[40] Wright, M., J. Wood, et al. (2008). "Mapping levels of palliative care development: a global view." Journal of Pain & Symptom Management 35(5): 469-485.

[41] Anquinet, L., J. A. C. Rietjens, et al. (2012). "The Practice of Continuous Deep Sedation Until Death in Flanders (Belgium), The Netherlands, and the U.K.: A Comparative Study." Journal of Pain and Symptom Management 44(1): 33-43.

[42] Abarshi, E., M. A. Echteld, et al. (2011). "Use of Palliative Care Services and General Practitioner Visits at the End of Life in The Netherlands and Belgium." Journal of Pain and Symptom Management 41(2): 436-448.

[43] Dadd, G., N. de Cinque, et al. (2004). "Bereavement support for families following the death of a child from cancer: practice characteristics of Australian and New Zealand paediatric oncology units." Journal of Paediatrics and Child Health 40(3): 131-135.

---

[44] Bosnjak S, Murer MA, Ryan KM, Leon MX, Madiye G. Improving the availability and accessibility of opioids for the treatment of pain: The International Pain Policy Fellowship. Support Care Cancer 2011;19(8):1239-1247.

[45] Davies AN, Dickman A, Reid C, Stevens AM, Zeppetella G. The management of cancer-related breakthrough pain: Recommendations of a task group of the Science Committee of the Association for Palliative Medicine of Great Britain and Ireland. Eur J Pain 2009;13(4):331-338.

[46] Galvez R. Variable use of opioid pharmacotherapy for chronic noncancer pain in Europe: causes and consequences." J Pain Palliat Care Pharmacother 2009;23(4):346-356.

[47] Borasio, G. D., P. J. Shaw, et al. (2001). "Standards of palliative care for patients with amyotrophic lateral sclerosis: results of a European survey." Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders 2(3): 159-164.

[48] Marinangeli F, Ciccozzi A, Leonardis M, et al. Use of strong opioids in advanced cacer pain: a randomized trial. J Pain Symptom Manage 2004;27(5):409-416.

[49] Constantini M, Ottonelli S, Canavacci L, Pellegrini F, Beccaro M. The effectiveness of the Liverppool care pathway in improving end of life care for dying cancer patients in hospital. A cluster randomised trial. BMC HSR 2011;11(13).

[50] Tanneberger S, Pannuti F. The Bologna Hospital-at-Home: A model for cost-effective care of advanced cancer patients in developing countries. Natl. Med. J. India 1998;11(5):231-235.

[51] Man JP, Weinkauf JG, Tsang M, Sin DD. Why do some countries publish more than others? An international comparison of research funding, English proficiency and publication output in highly ranked medical journals. Eur J Epidemiol 2004'19;811-817.

[52] Cohen J, Bilsen J, Fischer S, et al. End-of-life decision-making in Belgium, Denmark, Sweden and Switzerland : does place of death make a difference? J Epidemiol Community Health 2007;61(12):1062-1068.

[53] Ruperto, Nicolino, and Alberto. International research networks in pediatric rheumatology: the PRINTO perspective. Curr Opin Rheumatol, 2004;16(5):566-570.

[54] Bhutta BA. Ethics in international health research: a perspective from the developing world. Bull. World Health Organ 2002;80(2):114-120.

[55] Sidaway JD. In other worlds: On the politics of research by 'First World' geographers in the 'Third World'. Area 1992;24:403-408.

[56] Nobel C. Why global health researchers should climb down from the Ivory Tower. 2014. Available from: http://www.forbes.com/sites/hbsworkingknowledge/2014/08/06/why-global-health-researchers-should-climb-down-from-the-ivory-tower/. Accessed September 09, 2014.

[57] De Raeve L. Ethical issues in palliative care research. Palliat Med 1994;9:165-170.

[58] Casarett DJ, Karlawish JHT. Are special ethical guidelines needed for palliative care research. J Pain Symptom Manage 2000;20(2):130-139.

[59] Eunice Kennedy Shriver National Institute of Child Health and Human Development. Global Network for Women's and Children's Health Research. 2014. Available from: https://www.nichd.nih.gov/research/supported/Pages/globalnetwork.aspx. Accessed September 09, 2014.

[60] Bloom DE and Canning D. Commission on Growth and Development. Population Health and Economic Growth. 2008. USA: The World Bank Group.

[61] The World Bank. Financing the Post-2015 Development Agenda. 2015. Available from: http://www.worldbank.org/mdgs/post2015.html. Accessed January 10, 2016.

[62] Knaul F, Nigenda G and Zuñiga P. "Case Study: Costa Rica," in Long-term care in developing countries: ten case-studies. Brodsky J, Habib J and Hirschfield (Eds). 2003. Geneva: WHO.

[63] Fletcher DS, and Pank JT. Palliative care improves quality and reduces costs. Available from: http://www.medscape.com/viewarticle/770980_3. Accessed 03 July, 2015.

[64] FAO Corporate Document Repository. HIV/AIDS Turning into a Development Issue. 2003. Available from: http://www.fao.org/docrep/006/Y4973E/y4973e05.htm. Accessed 12 February, 2015.

[65] Curiale, V. World-wide literature survey on geriatric palliative medicine. EGM 2011;2(1):6-11

[66] Sampson EL, Ritchie CW, Lai R, Raven PW, Blanchard MR. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. Int Psychogeriatr 2005;17:31-40.

[67] Fowell A, Johnstone R, Finlay IG, Russell D, Russell IT. Designs of trials with dying patients: a feasibility study of cluster randomisation versus randomised consent. Palliat Med (2006);20(8):799-804.