A life or 'good death' situation? A worldwide ecological study of the national contexts of countries which have and have not implemented palliative care.

Abstract

Context: Palliative Care advocates argue that service implementation is feasible in all settings. Yet, services have developed patchily in low and middle-income settings. Beyond Human Development Index indicators, there has been limited engagement with the broader development challenges facing nations tasked with implementing palliative care.

Objective: To describe how indicators of national development relate to levels of palliative care services in 207 countries around the world.

Methods: Ecological study to identify relationships between potential predictor variables and the level of national palliative care development. A total of 28 predictor variables from the following 6 domains were selected using hypothesised relationships with levels of palliative care development: disease demographics, socioeconomics, health systems, politics, demographics and economics. The outcome variable was level of national palliative care development on a six-point scale. Spearman's correlation was used to measure the strength of the association.

Results: Twenty-six out of 28 variables were statistically significantly associated with levels of palliative care development in 207 countries. Palliative care is more developed in countries with high: percentage of deaths from non-communicable disease; population proportion aged 65+; gross national income and tourism. Development is lower in countries with high levels of: political corruption; infant mortality; deaths by infectious diseases; and weak democracy. Prevalence of under-nourishment and levels of private health expenditure were not significantly associated with palliative care development.

Conclusion: Palliative care development is highly consistent with broader national development indicators. It is less in countries where sudden deaths are more likely and benefits from palliative care provision are likely to be very limited. In such countries, resources may be prioritised towards life prolonging therapies and key aspects of palliative care need only be implemented prior to fully integrated palliative services. Findings suggest that there may be a 'tipping point' in societies, where the relative need for life-prolonging therapies becomes less than the need for integrated palliative care services.

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Context

The first modern palliative care services emerged in Europe and North America in the 1960s.[1] Since then, the philosophy and practice of palliative care has spread and services now exist in 136 of the world's 234 countries.[2] This represents an exponential spread of palliative care practice, since its modern conceptualization. Palliative care advocates argue that service implementation is feasible in all settings.

Yet, services have developed inconsistently in low and middle-income settings and inadequate access to palliative care remains a global norm. The authors of the only global mapping study attribute global development to a wide range of qualitative factors [Table 1]. They also report that palliative care development is associated with Human Development Ranking. However, these findings do not inform us of the broader development challenges facing nations who have not implemented palliative care, or have done so to a very limited extent.

Table 1. Factors influencing the development of palliative care services

National governments are now tasked with implementing the World Health Assembly Palliative Care Resolution which states that palliative care should be integrated at all levels of health systems.[3] This is at the same time as governments make efforts towards achieving the Sustainable Development Goals (SDGs), with many of these goals already behind schedule.[4] With limited finances available, policymakers must make decisions regarding where resources should be allocated. It is therefore important to understand the broad development challenges facing countries tasked with implementing palliative care. Only then can sensible recommendations be made regarding how palliative care can be implemented in health systems worldwide.

We aimed to describe how indicators of national development relate to levels of palliative care services in nations around the world.

Methods

We conducted a cross-sectional ecological study to explore relationships between a range of demographic, health, economic and political variables, and level of palliative care development in 207 countries.

Data sources

We used the Worldwide Palliative Care Alliance (WPCA) 2011 global rankings as the outcome variable for levels of palliative care development. A global update of the WPCA project was published in 2014, however, this did not include new country rankings. An update to the country rankings is planned for 2019 and future comparative analysis of the 2011 and 2019 data is encouraged.

Predictor variables extracted were drawn from several globally collated macro-datasets available in the public domain: the World Bank Development Indicators,[5] the Economist Intelligence Unit (EIU),[6] the Pain and Policy Studies Group[7] and Transparency International.[8] Within such datasets, data are collected on variable years, from heterogeneous sources and collated by global agencies. All data were extracted in 2014.

Variable selection

We adapted the WPCA country categorisations of palliative care development into a six-point ordinal scale as the outcome variable (one is lowest and six is highest). Predictor variables were selected using a theoretical approach, based on World Health Organization's (WHO) guidance on a public health approach to palliative care development[9] and Global Social Policy perspectives.[10]

Predictor variables were selected iteratively, based upon theoretical hypotheses that they may be relevant to palliative care development. The justifications for variables included are presented as Supplementary file 1 along with explanation of rankings where appropriate; for example, a low Corruption Index Score indicates high levels of corruption. In total, 28 variables from six domains were included [Table 2].

Table 2. Variables selected with a hypothesised relationship with palliative care development

Data cleaning

The WPCA study uses United Nations country classifications and provides palliative care rankings for 234 countries. However, the World Bank uses a different country classification approach and publishes data for 207 countries only. As such, countries with a WPCA ranking but no World Bank Data available were removed from the analysis. As shown in Table 3, the proportion classified by each palliative care variable was not unduly altered by using the World Bank compared with the WPCA grouping.

Table 3. Distribution of countries within country classification groups

Available data from macro datasets were imported in to SPSS IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp. As predictor variable data are not published annually by global organizations, a five-year period (2007-11) preceding the outcome variable (2011) was agreed amongst the research team as a reasonable time-frame within which to explore associations between variables. An exception to this rule was made to include disease and health system data from 2000 as this was the only suitable dataset usable prior to 2011. Available data were consolidated and matched to countries.

There were missing data for all variables (Supplementary appendix 2). Where data were missing for predictor variables, cases were excluded from the analysis. This process was documented, listing the years of data included for each country as well as the total number of countries included within each correlation test.

Following data cleaning, 28 predictor variables and 207 countries with outcome data were included in the analysis.

Analysis

Spearman's correlation was calculated to measure the strength of association between development variables and level of palliative care development.[11] We described the strength of association between variables using Cohen's co-efficient scale, ranging from zero to perfect.[12] The significance level was set at 5%.

We explored the possibility of conducting ordinal regression to examine predictor variables together; however, this was not attempted for three reasons. Firstly, we ran collinearity diagnostics in SPSS and found high levels of collinerarity, meaning that dependents variables would not independently predict the outcome variable.[13] Secondly, there was not 'proportional odds' between categories of the independent variable, that is the degree of difficulty of moving between country groups is not equivalent. Lastly, it does not improve the overall narrative of the study to isolate fewer variables of

particular statistical importance for palliative care development, when no causal relationships can be inferred. Our findings should therefore be understood as exploratory and no predictive relationships between variables are inferred.

Results

A total of 26 out of 28 variables were significantly associated with levels of palliative care development [Table 4]. Results show that theory-driven hypothesised relationships are highly explanatory of palliative care development. Our study provides data to show that palliative care is underdeveloped in countries which face significant broader development challenges and that palliative care provision increases as these broader challenges reduce or change.

Table 4. Associations between demographic, economic, health and political variables and level of palliative care development across 207 countries

The six variables with the strongest relationship to palliative care are presented in Fig 1, the direction of each relationship between the variables supports the hypothesised reasons for inclusion. Only 'prevalence of undernourishment (% of population)' and 'Health expenditure, private (% of GDP)' were not significantly associated with palliative care development.

Fig 1. Predictor variables with the strongest relationship with palliative care development (n=6)

Palliative care is more developed in countries with high: percentage of deaths from non-communicable disease, population proportion aged 65+, gross national income and tourism. Development appears to be responsive to the needs of ageing populations, with level of development higher in countries with high life expectancy and percentage of population over 65. The strong relationship between palliative care development and tourism supports studies which show that tourism can promote health within host low and middle-income countries as well as the likelihood of high tourism rates in high-income countries.[14] That development is higher in countries with predominantly urban populations supports research identifying the logistical challenges of providing services to rural populations.[15] Higher levels of development in countries with a high percentage of death rates from non-communicable diseases perhaps reflects the early development of palliative care as an end of life cancer intervention.

Palliative care is less developed in countries with weak democracy and high levels of: political corruption, infant mortality rates and deaths by infectious disease. This suggests a lack of political will to establish palliative care services in contexts where most people die at a younger age from infectious disease and where deaths are more likely to occur after a short period of illness. Such countries may be focussing resources upon tackling infectious diseases (where solutions are less complex than to tackling NCDs) at the expense of palliative care.[16]

Countries with no, or limited palliative care provision are also associated with: low overall health system strength, high mortality rates at younger ages and high levels of societal inequality. These findings support the overall understanding that countries with limited palliative care services face significant structural problems in the delivery of any form of social welfare. Such countries are also likely to be net-receivers of Overseas Development Assistance (ODA), which supports suggestions that global funding agencies are not promoting palliative care as a key aspect of international development.[17]

Lastly, outlier countries were found across all included variables. Most notably, Uganda and Romania both appear as outliers across several variables, with high levels of palliative care development in the context of significant broader development challenges. Another particularly noticeable outlier

was 'Monaco', with 'no known palliative care activity' in the context of having the highest ratio of hospital beds per 1000 in the world and known wealth and prosperity. These findings encourage renewed attention upon how services in Uganda and Romania have developed to a high level in spite of challenging circumstances. However, other outlier countries encourage caution about the validity of some country rankings, given the unexpected and unlikely finding of Monaco as a place without any palliative care at all.

Discussion

This exploratory study provides data to show that international palliative care development is highly consistent with broader national development indicators. Our findings support an overall understanding that countries which have limited palliative care services face significant structural problems in the wider delivery of social welfare; with a particular challenge being high levels of corruption and weak democracy, which have undermined the development of high quality health services. In such circumstances, millions of people continue to die from diseases of poverty (e.g. diarrhoea) which are either treatable, or preventable in the first place.[18]

A life or 'good death' situation?

In countries where most deaths are still caused by communicable diseases, the dying process is more likely to be relatively brief (whilst noting that some communicable diseases such as HIV are increasingly of chronic course).[19] This means that most need for palliative care will occur suddenly, in response to 'unexpected' end to life, and not for progressive illness. This limits the benefits which may accrue from the provision of palliative care. In national contexts where most deaths are caused by non-communicable diseases, improved life expectancies have come with the associated challenges increased prevalence of illness of old age and chronic complex. In such circumstances, the dying process is likely to be prolonged, with patients living with serious illness and associated problems for a significant period of time of months to years. This increases the overall need for palliative care and the value proposition which services may represent.

Our analysis suggests that palliative care services *are* developing to a high level in such circumstances and that development occurs in response to increased longevity of need, relative to other health concerns. It also suggests that there may be a societal 'tipping point', where healthcare priorities switch from delivery of life-extending therapies (plus basic elements of palliative care), to services aimed at ensuring quality of life as a public health priority – with ongoing appropriate curative services. Societies must plan for when any 'switch', must take place and not repeat the mistakes of many health systems in richer countries, where success of acute care provision has often developed into delivery of expensive and futile treatments at the end of life. This has come at the expense of delivery of appropriate supportive and palliative care measures, in particular for those with non-malignant disease.[20]

What then are the consequences for the feasibility of implementing the WHA Resolution all settings?

A key argument for the feasibility of palliative care is that implementation may be cost-saving to health systems.[21] By reducing use of expensive 'futile' curative treatments in advanced disease, costs may be saved by appropriately directing patients towards palliative care. However, in countries where palliative care services have not developed, it must be acknowledged that rolling out new palliative care services will be an *additional* cost to already burdened healthcare systems that are struggling to provide vaccinations for preventable disease and inexpensive curative treatments for otherwise fatal illnesses that are rarely fatal in high-income countries.[22]

This is in spite of the potential for palliative care to cost-effective through the reduction of costly ineffective therapies.[23] Over-treatment of medical problems is a present and growing problem around the world and great inequalities and inequities exist between (and within) nations in terms of access to appropriate care.[24] However, under-treatment and lack of access to the most fundamental appropriate health care remains the dominant reality for most people in low and middle-income countries. Whilst a key tenet of palliative care is to accept death as a natural process, this does not mean that we should not intervene where the lives of otherwise healthy people may be saved by simple, inexpensive and appropriate medical treatment.

Within this context, calls for accelerated development of palliative services must be informed by in-depth understanding of national development contexts, local needs and opportunity costs. It is important that priority palliative interventions are available to those who need them. This raises the need for research to illuminate what the priority issues are for dying patients in all world contexts. Whilst not forgetting holistic approaches to palliative care, development should focus upon 'key issues' for patients, prior to fully integrated palliative services. Alongside this, healthcare systems in low and middle-income countries must continue to strive to reduce deaths from avoidable and treatable causes.

Limitations

The non-uniformity of methods employed to collect national-level data and consequent heterogeneity of data means that the validity of conclusions of this study must be treated with caution. Furthermore, the WPCA rankings themselves are problematic, given that they are commonly based upon self-reported data and researcher judgements. Some data were also missing for all variables. This means that some countries were excluded [Table 3] which introduces a small but systematic bias, with richer countries over-represented. In spite of these limitations, our results are based upon 'comparable cases', derived from a single outcome variable. As with all ecological studies, there is an inherent risk of 'ecological fallacy'. We acknowledge that by using 'country' as the unit of analysis, our results may not reflect the experiences of individuals, or inequities within such countries given that health funding and palliative care policies may be at a sub-national. Nevertheless, our observational study illuminates understanding of the broader national problems and challenges facing countries which are yet to implement palliative care to a high level and provokes debate about the future development of palliative care.

Finally, our cross-sectional study offers a snapshot of the global situation in 2014. Since data were collated, there have been numerous global developments, including efforts to implement the 2014 Palliative Care Resolution and the SDGs. In spite of challenges, such policy developments as well as ongoing improvement efforts will have no doubt improved palliative care development within countries. For example, palliative care has been included as an important part of the National Cancer Control Program in Afghanistan, a country previously with 'no known palliative care activity' – immediately altering its country ranking.[25] There may also have been setbacks to national development in some countries around the world. Publication of new country rankings will facilitate comparative research to improve understanding of how national development contexts interact with palliative care development.[26] Further work may also investigate how national indicators of development interact with palliative care development to test emerging hypotheses. For example, do high levels of arriving tourists indeed promote palliative care development in nations and what are the consequences of this?

Conclusion

Our findings suggest that there may be a 'tipping point', where the relative need for life-prolonging therapies becomes less than the need for integrated palliative care services. Future research could usefully focus upon how to identify any such tipping-point in specific national contexts. This would allow appropriate preparation for new challenges of ageing populations, associated increases in chronic/degenerative illnesses and survivorship, when basic interventions to prevent and avoid deaths from avoidable causes have been successfully implemented.

Disclosures and Acknowledgments

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