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**A Global Social Policy Analysis of International Palliative  
Care Development**

Submitted in fulfilment of the requirements for the degree of Doctor of  
Philosophy

School of Health and Related Research (ScHARR), University of Sheffield

February 2016

## **Declaration**

I hereby declare that this thesis submitted for the degree of Doctor of Philosophy is the result of my own research, except where otherwise acknowledged. No portion of the work presented in this thesis has been submitted for another degree or qualification to this, or any other university or institution.

Joseph Clark

February, 2016



## Abstract

A global lack of pain and palliative care services means that millions of people each year spend their last weeks and days suffering serious, but avoidable physical and psychological pain. More usually understood as a national issue, this multiple methods study considers why palliative care should be considered an issue for the international development community.

Use of Global Social Policy as a theoretical lens to view development reveals opportunities for palliative care to make gains within the incoming global health priority of achieving Universal Health Coverage. It is argued that there is a need to move beyond consideration of palliative care as a moral concern towards new ways of 'framing' the issue. Presentation of palliative care as being economically beneficial is therefore encouraged. By doing so may allow the presentation of palliative care as an important element of international development and attract new funding streams.

A systematic review reveals a lack of 'international evidence' for palliative care, particularly in low and middle income countries. More encouragingly, opportunities are revealed for existing policies and practices to be 'transferred' to other similar settings. Yet, an analysis of the national contexts from which palliative care has (and has not) developed shows that countries which have not developed palliative care are likely to face significant challenges in the delivery of basic healthcare. This raises serious questions regarding how such countries can *also* integrate palliative care into their health systems.

International palliative care experts were consulted to find out how they thought the field can move forwards through global advocacy. The far-reaching benefits of palliative care encourage the need for palliative care to be constructed in new ways. However ongoing disunity regarding whether palliative care is a long term approach or an end of life intervention threatens to undermine how activists can construct tractable arguments for palliative care to policymakers.



## **Publications and Presentations Arising from This Thesis**

Clark J, Gardiner C, and Barnes A. International palliative care research in the context of global development: a systematic mapping review – 14<sup>th</sup> World Congress for the European Association for Palliative Care, Copenhagen, Denmark, 8<sup>th</sup> May, 2015. (Poster presentation)

*Manuscript currently undergoing peer-review with BMJ Supportive and Palliative Care*

Clark J. Systematic Mapping Review of International Palliative Care Research. EAPC 2015 14<sup>th</sup> World Congress of the European Association for Palliative Care. 2015. *European Journal of Palliative Care*. United Kingdom: Haywood Publishing Group (Conference abstracts)

A Global Social Policy Analysis of International Palliative Care Development. Delivered at Open Society Foundation. Reflections on Advocacy Strategies to Advance Palliative Care: A meeting hosted by the Open Society Foundation. New York. November 15<sup>th</sup>. Invited presentation.



## Acknowledgements

The completion of this thesis has been for the most part enjoyable, at times extremely challenging but ultimately very rewarding. It has been achieved for the most part by long hours working in the office, at home and in coffee shops, but would not have been possible without the support of a number of people who I must thank here.

First, I must thank my supervisory team; Clare Gardiner, Amy Barnes, Mike Campbell and for a short time Alexandra Kaasch. This journey for all of us has seen international travel, emigration, new arrivals and jobs. During all of this I have been allowed to work independently whilst never being any less than fully supported and encouraged and I must thank each of the team for the kind guidance, most particularly at the end of this process, which I feel has given me the ‘full PhD experience.’ Most particularly I am grateful to Clare who has been part of the project from inception up to completion.

Secondly, I am grateful to my study participants who I am unable to name here, but whom a significant contribution to the study, through their expertise, insight and enthusiasm for the project. I must also thank one participant in particular, for giving me the opportunity to present this work at the Open Society Foundation in New York and contribute to a global advocacy strategy meeting for palliative care.

Thirdly, I must thank friends and colleagues who have helped me through this journey, either through conversations about the work or taking me away from the desk. In particular I must thank: Kate Jackson who was invaluable in helping me recruit notable experts in the field to my study, Dr Henock Taddese, for being a willing sounding board, source of guidance and for always being ready with Ethiopian coffee, Amy Whitehead for keeping me light-hearted and Jiban Karki who is a constant reminder of what is important in the world.

Lastly I must thank my family for putting up with me throughout this process, specifically Tom, Ray, Phil, Dad and most particularly my Mum, who has been a crutch, friend and unwavering provider of dinners, advice and more.



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## List of Acronyms

AAA	Accra Agenda for Action
CDR	Crude Death Rate
CDs	Communicable Diseases
DAH	Development Assistance for Health
DoH	Department of Health
EAPC	European Association for Palliative Care
EIU	Economist Intelligence Unit
GDP	Gross Domestic Product
GCP	Good Clinical Practice
GNI	Gross National Income
GSP	Global Social Policy
HDI	Human Development Index
HRW	Human Rights Watch
IAHPC	International Association of Hospice and Palliative Care
IFIs	International Financial Institutions
IMF	International Monetary Fund
INCB	International Narcotics Control Board
INGOs	International Non-Governmental Organizations
IPCI	International Palliative Care Institute
IOELC	International Observatory on End of Life Care
IO	International Organization
LCP	Liverpool Care Pathway
MDGs	Millennium Development Goals
NCDs	Non-Communicable Diseases
ODA	Overseas Development Assistance
OECD	Organization for Economic Co-Operation and Development
OSF	Open Society Foundation
OSI	Open Society Institute
PDAE	The Paris Declaration on Aid Effectiveness

PIS	Participant Information Sheet
QALY	Quality Adjusted Life Year
QoD	Quality of Death
QoL	Quality of Life
RCT	Randomised Controlled Trial
REC	Research Ethics Committee
SALY	Suffering Adjusted Life Year
SDGs	Sustainable Development Goals
TNCs	Transnational Corporations
TRIPS	Trade-Related Aspects of Intellectual Property Rights
UHC	Universal Health Coverage
UK	United Kingdom
UN	United Nations
UNICEF	United Nations Children's Fund
UNHCR	United Nations Human Rights Council
US	United States
USAID	United States Agency for International Development
WHA	World Health Assembly
WHO	World Health Organization
WHPCA	Worldwide Hospice Palliative Care Alliance
WPCA	Worldwide Palliative Care Alliance
WTO	World Trade Organization

## Chapter One

### High Level Overview of the Thesis

Globally, over 60 million people die each year, many of whom do so having spent their last days and weeks of life enduring extreme suffering due to a lack of pain treatment and appropriate care.<sup>i</sup> In a context of increasing and ageing global populations, these numbers are set to rise with increased strains placed upon health systems threatening their very sustainability.<sup>ii</sup> In this regard, this thesis considers how palliative care can contribute to alleviating these global social problems.

The thesis starts [Chapter Two] by examining claims that there is a global need for palliative care. This need is shown to occur due to a lack of availability of pain treatment, as well as medical approaches which focus upon aggressive treatment at the expense of delivering appropriate care.<sup>iii</sup> National studies are identified which show that palliative care is an approach which can improve the quality of life of people living with serious illness and their families as well as reduce overall costs to health systems.<sup>iv</sup> Yet, in spite of this value proposition and the fact that palliative care services now exist in 136 of the world's 234 countries, there remains a significant gap between supply and demand for services.<sup>v</sup> Existing narratives of palliative care development have focussed upon national-level processes and this chapter shows that there has been little global leadership.

Prioritisation by global health actors is however, shown to hold the potential to significantly accelerate palliative care development, through global regulations, resolutions and financing.<sup>v</sup> In this regard, in 2014 the World Health Assembly passed a Resolution calling for national governments to integrate palliative care into health systems.<sup>vi</sup> However, although there are suggestions that access to palliative care should be a universal human right, the field remains under-theorised, underfinanced and underdeveloped. Chapter Two therefore concludes by presenting the overall research question of the study:

*Can the global development of palliative care be furthered through increased understanding of global policymaking processes and the presentation of palliative care as an international development issue?*

Chapter Three moves on to apply a Global Social Policy (GSP) perspective to palliative care development. Key actors in global health are identified as well as their relative potential to influence health policies and practices within nations. Competing narratives are presented for how policies

and practices spread internationally.<sup>viiiviii</sup> Additionally, it is suggested that in order to attract global financing, advocacy needs to move beyond conceptualisations of palliative care as a human rights issue and use different ‘frames’ with which to influence diverse policymakers. Importantly, it is noted that global health policies are often formulated due to considerations of; economic utility, available evidence, the severity of problems as well as how straightforward they may be to solve.<sup>ix</sup>

Chapter Four presents the overall methodological approach and the multiple methods design used to allow this research question to be answered. To do so, tenets are drawn from positivism to inform a largely interpretivist project. Justification is provided for an iterative research process which saw the adoption of diverse methods; systematic review, quantitative analysis using correlations and qualitative interviewing of key experts in the field of international palliative care. Detailed consideration of each of these methods is presented in subsequent chapters. It is also made clear that a GSP perspective will be adopted throughout the study as a theoretical lens through which to understand the place of palliative care within broader global health discourses.<sup>v</sup>

Chapter Five presents a systematic mapping review of international palliative care research. This chapter uncovers the extent to which researchers are providing internationally relevant evidence of the transferability of palliative care policies and practices. Additionally, whilst research capacity in low and middle income countries is low, the extent to which researchers from richer nations are supplementing the evidence base for palliative care in other settings is examined. It is shown how there is little international economic evidence for palliative care and little interventional research which advocates can present to policymakers. Additionally, studies are identified which consider ‘model services’. That is, instances of good practice which researchers profess may be relevant in other resource-similar settings.<sup>x</sup>

Chapter Six moves on to consider such claims and investigates the structural contexts in which palliative care has (and has not) developed to a high level. A broad range of indicators are used, drawn from several development domains (disease demographics, health systems, socioeconomics, country demographics, politics and economics) to consider their relationship with palliative care development. It is shown that nations which are ‘similar,’ in terms of political context, demographics and socioeconomic indicators of development, have developed palliative care to similar levels. Whilst this raises the possibility that palliative care models may be transferrable to other ‘similar’ settings, it is also shown that nations which have not developed services are likely to face serious challenges in the provision of welfare services more broadly. It is therefore reiterated, that in order

for the 2014 WHA Resolution to be implemented and for palliative care to be considered a priority within the new global health priority of achieving Universal Health Coverage, that focussed advocacy is required in order to draw the attention of policymakers and global funding agencies to the importance of palliative care.

Chapter Seven builds on these findings by eliciting the views of experts in the field of international palliative care regarding the adequacy of existing global advocacy efforts and how these efforts may be refined in order to progress development. Six thematic categories were generated based upon participant responses which reveal both serious barriers and opportunities for the field of palliative care to move forwards. These are: 1) Education; changing the culture of medicine; 2) Palliative care as an area of global need; 3) Broad benefits of palliative care and the consequences of its absence; 4) Prioritisation within health systems and organization of services; 5) Global Policies, Leadership and Actors for change; and 6) Framing palliative care.

Within this chapter, a wide range of opportunities are also identified for the further development of palliative care. Notably, 'improving access to pain treatment' is identified as the most pressing and solvable problem. Yet, many of the arguments presented by participants had a 'time dependency'. That is to say, almost all 'benefits' of palliative care suggested by participants, were contingent on its introduction *either* as a long term or intervention or as end of life care. This lack of clarity regarding just what palliative care *is*, is identified as the most serious tension within the field.

In Chapter Eight, the thesis concludes by arguing that in spite of clear global need, there are serious questions regarding the development model which palliative care has followed. There is an apparent ongoing reliance upon individual 'pioneers' and organizations, which provide short-term funding, leaving palliative care facing an uncertain future. In this regard, key implications of the study are presented for; the organization of services, the research community, policy and advocacy. Innovative suggestions are made for how the problem of lack of palliative care can be re-defined. Strategic advice is also presented for how researchers can equip advocates with policy-relevant evidence to appeal to different national and global health policymakers.

Note on the text: to aid the reader, references are presented at the end of each chapter to allow easy cross-referencing.

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## Chapter Two

### Understanding the global need for palliative care

#### Introduction

Each year, worldwide close to 60 million people die from serious illness.<sup>i</sup> Many of these people spend the last few days and weeks of their lives enduring extreme suffering due to a lack of appropriate care and pain treatment.<sup>ii</sup> As the world's population increases, the number of people who will endure extreme suffering at the end of life will also increase if appropriate interventions are not developed to aid these people. Palliative care, a complex intervention comprising of "treatment of pain and other problems, physical, psychosocial and spiritual [WHO, 2015]"<sup>xviii</sup> has been suggested as a feasible and appropriate intervention in order to meet the needs of people living with serious and life-threatening illnesses. However, globally palliative services remain underdeveloped and the need for palliative care sits alongside many other global health challenges with valid claims for policy attention.<sup>iii</sup> Furthermore, in recent times, global health efforts have focussed upon increasing life expectancy through attempts to eradicate illness such as malaria,<sup>iv</sup> rather than on providing appropriate care to people undergoing the universal experience of dying.

This study emerged to answer questions regarding the seriousness of the problem of absence of palliative services as well as to consider if palliative care development should be prioritised as a global health issue. There is demonstrable global need for palliative care, seen most clearly by the overwhelming lack of access to pain-relieving medications for people suffering from conditions which are known to cause severe pain.<sup>v</sup> However, the current rate of global development is inadequate for meeting the needs of patients and families for pain and palliative treatments. Moreover, existing conceptualisations of how services have developed focus upon community action or nation-level leadership and there is an apparent lack of global leadership for palliative care.<sup>vi</sup>

Global health actors and policies wield significant influence over national health systems worldwide.<sup>vii</sup> However, the broad absence of engagement from global level actors with palliative care issues may be considered a significant limiter on development. Moreover, existing explanations for the global development of palliative care, fail to take into account forces which operate at global level to shape national healthcare policies and practices. That is, current accounts of how palliative

care has developed, do not draw upon theoretical approaches to understanding global policymaking processes, nor the place of palliative care within broader global discourses on health.

On this basis, a Global Social Policy (GSP) theoretical stance was adopted throughout the study. GSP is a discipline which places a high level of importance upon how global level forces operate to influence policies and practices within nations.<sup>vii</sup> Further detail will be given regarding the theoretical underpinnings of GSP in Chapter Three, however, in brief, GSP scholars seek to understanding competing explanations for how and why certain policy issues are prioritised over and above other valid claims. Increased understanding of such issues may be fruitful in furthering the global development of palliative care.

Advocates profess that absence of palliative care is a human rights issue.<sup>viii</sup> Indeed this study emerged from personal experiences witnessing the severity of suffering which people endure due to the absence of services as well as the wide-reaching benefits which follow the introduction of palliative care. Palliative care is however a relatively new field of healthcare, the professed benefits of which are not generally well understood<sup>ix</sup> and on this basis, a critical standpoint was adopted throughout the study: viewing palliative care not from a vested interest but from a position outside the field to consider the strength of the evidence-base for palliative care. This also allows an unbiased position through which to assess the validity and clarity of the arguments which activists deliver to policymakers in order to advance the field through advocacy.

Conceptualising the past and potential future development of this emergent field of healthcare raises a series of important and diverse questions. Key questions addressed within the study centre around how palliative care has developed internationally thus far, how further rollout of services may be accelerated as well as how to overcome the significant barriers which exist to further development. Moreover, palliative care is considered as a healthcare issue more broadly, in terms of its place and importance alongside other global healthcare challenges. As such, this study adopted an iterative methodological approach, which saw different research methods utilised in order to answer emerging questions.

Different questions and arguments emerged throughout this thesis. However the first stage was to develop an overarching research question for the study. In order to do so, it is first important to establish what palliative care is, what its benefits are and what problems are caused by its absence. Moreover, given that the first articulation of 'palliative care' was made only in the 1960s, it is

appropriate to consider what is known about how palliative care as a modern multidisciplinary practice has spread internationally.<sup>x</sup>

### **What is palliative care?**

Palliative care is the term used to describe a multidisciplinary approach to treating and caring for people living with serious and life-threatening illnesses and their families/support systems.<sup>xviii</sup> It is an approach to the treatment of people living with serious illnesses which recognises that illness impacts upon quality of life across multiple dimensions and can lead to pain and other physical symptoms as well as psychosocial and spiritual suffering. Palliative *medicine* is now recognised as a medical specialty or sub-specialty in several countries and may be delivered in all healthcare settings as well as in patients' homes.<sup>xi</sup> However 'hospices' are the clearest example of institutions where palliative care is delivered. The first modern hospice was established in the United Kingdom [UK] by Cicely Saunders in the 1960s and services now exist in all regions of the world although there are significant inequalities and inequities of access both between and within nations.<sup>xii</sup>

The discipline of palliative care emerged from a recognition that often medical practitioners' approach to treatment is to focus upon curative treatment of illness, without acknowledgment of the need to address broader symptoms and suffering. Here, Eric Cassel, an oncologist and seminal actor in the early development of palliative care in North America in the 1980's describes this circumstance:

Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as the twin obligation of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself [1982. P639.]<sup>xiii</sup>

In the 1960s the founder of the modern hospice movement, Cicely Saunders, termed suffering of this manner 'total pain' - a term which continues to be used today.<sup>xiv</sup> Dating the origins of palliative care to this period serves as a reminder that this is a relatively new field of healthcare.

Palliative care is deemed to be appropriate for all children and adults living with a serious illness.<sup>ii</sup> Historically, it has been considered as an end of life intervention (i.e. provided to people very close to death). However, more recently it has been argued that it should be commenced upon diagnosis of a serious illness alongside curative efforts.<sup>xv</sup> Thus, palliative care may be considered an appropriate intervention from the point of diagnosis, up to and beyond bereavement. Another historical legacy is that palliative care was once considered appropriate only for cancer patients, however, this understanding has been altered and it is said to be a form of care which is appropriate for any person living with a serious, life-threatening condition including both infectious and non-communicable diseases.<sup>xvi</sup> In addition to holistic care of patients, palliative care acknowledges that illness affects not only patients, but also impacts negatively upon the health and wellbeing of their families who often act as informal carers. Therefore palliative care treats 'patients, families and lay carers' as the unit of care.<sup>xvii</sup>

Despite associations with the end of life, palliative care is a complex intervention comprising different elements addressed below, which 'aims to neither hasten nor postpone death', and 'treats dying as a normal process' though may be introduced from diagnosis.<sup>xviii</sup> The most widely used definition of 'palliative care' was articulated by the World Health Organization (WHO) as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [WHO, 2002].<sup>xviii</sup>

The term may be considered problematic, due to conflicting definitions of 'palliative care' as well as conflicting and complementary additional terms, such as 'hospice' and 'end of life care', which are often inappropriately used interchangeably.<sup>xix</sup> In North America for instance, 'hospice care' is something which is seen as being a distinct form of palliative care<sup>xx</sup>, whereas in other settings, hospices are perceived as institutions which deliver palliative care, often towards the end of life rather than from diagnosis.<sup>xxi</sup>

Palliative care is often delivered by a multi-disciplinary field and may be considered to be a 'complex intervention' in that it is "made up of many components that act both on their own and in conjunction with each other [Nazareth I, 2015]".<sup>xxii</sup> This complexity presents challenges to the field both in terms of service delivery, with care often delivered in formal (i.e. hospitals) as well as

informal (patients' homes) healthcare contexts.<sup>xxiii</sup> Additionally, research and evaluation of palliative care is complex owing to the wide range of potential outcomes of interest.<sup>xxiv</sup>

### **Challenges to service delivery internationally**

That palliative care services exist in only 136 of the world's 234 countries, hints at both a lack of awareness of palliative care as well as the significant challenges in terms of delivering the multiple elements which comprise 'palliative care'.<sup>ii</sup> A clear example of a barrier which exists to the delivery of pain treatment is that many national governments continue to prohibit the use of essential pain-relieving opioid medications through regulations.<sup>xxv</sup> Often this circumstance arises due to a lack of awareness of the benefits to patients of opioids such as morphine, amongst policymakers and medical professionals as well as due to fears of misuse and addiction.<sup>xxvi</sup> However, in spite of convincing evidence of the efficacy of opioid medications for the treatment of pain, negative attitudes towards them persist.<sup>xxvii</sup> Fears of misuse are reinforced by the global regulation of opioids by the International Narcotics Control Board (INCB), which serves to limit access to opioids by treating them as 'drugs' rather than enabling their availability as 'medicines'.<sup>xxviii</sup>

Further challenges to service delivery exist in terms of a broad lack of palliative care awareness and education amongst health care professionals internationally, which means that there is a lack of human resources to deliver care.<sup>xxix</sup> Moreover, formulating and evaluating 'best practice' in palliative care is challenging due to the diversity of the palliative care patient population and need for services to be both context-specific and patient centred. For instance, additional challenges are said to exist in providing palliative care to rural populations.<sup>xxx</sup> Additionally, as palliative care should be culturally specific and in line with patient preferences, each patient must be treated holistically on a case by case basis.<sup>xxxi</sup> This raises challenges to health care professionals who cannot assume universal preferences and must elicit treatment preferences from patients and their families. For example, one aim of palliative care is to facilitate a patient to die in the location of their choice. However, whilst patients are often assumed to have a preference to die at home, one study which examined preference of place of death amongst Chinese people found a preference to die in a medical institution.<sup>xxxii</sup>

In this regard, the WHO recommends a public health strategy for the implementation for palliative care. This strategy emphasises the need for; appropriate policies, adequate drug availability, education of health workers and the public and implementation of palliative care at all levels of

society.<sup>xxxiii</sup> This global guidance is useful in terms of agenda setting, however the guidelines are not prescriptive and have not been evaluated to determine their relevance in low-income settings. Moreover, the high levels of diversity with regards to patient treatment preferences and potential treatment outcomes presented by the different elements of palliative care, supports suggestions that ‘palliative care’ must be adapted to specific national contexts.<sup>xxxiv</sup> Furthermore, aspects such as the current lack of education and availability of medications raise challenges not only to those delivering care but to researchers in producing an evidence base for palliative care. There are also specific ethical challenges inherent with conducting research with palliative care populations which must be addressed in order to produce evidence-based solutions.

The following section, therefore reviews some of the distinct challenges faced by researchers when conducting palliative care research.

### **Obstacles to high quality palliative care research**

Challenges to the production of an evidence-base for palliative care begin with the ethical complexity of conducting research upon vulnerable people.<sup>xxxv</sup> Palliative care patients may lack the mental capacity to provide informed consent to research studies or indeed may lose capacity during any longitudinal study due to the progression of illness.<sup>xxxvi</sup> Furthermore whilst Randomised Controlled Trials (RCTs) are considered the ‘gold standard’ in research, such trials are difficult to conduct in palliative care settings, whereby the process of randomisation itself is at odds with the aim of palliative care to allow patients choice of their own treatment.<sup>xxxvii</sup> Such circumstances are said to have served to limit the available evidence for the efficacy of palliative care and a lack of interventional research. Indeed, it has been suggested that there is reliance upon surveys and questionnaires in order to produce evidence for palliative care.<sup>xxxviii</sup>

Additional challenges to researchers also emerge from the aim of palliative care to meet patient-goals. As identified above, patient preferences are culturally and context specific.<sup>xxxix</sup> This raises further challenges as understandings of terms like ‘improved quality of life’ may vary between different groups.<sup>xl</sup> Furthermore, whilst there have been efforts to evaluate ‘quality of death’, there is of course no opportunity for the experiences of patients to be elicited once they have died and outcome measurement is therefore reliant upon learning the experiences of family members, health professionals and loved ones.<sup>xli</sup>

However, there is increasing evidence from around the world to support assertions that palliative care improves the quality of life of patients.<sup>xlii</sup> Additionally, studies have shown that palliative care can lead to positive experiences of illness and death for family members which in turn leads to improved outcomes following bereavement.<sup>xliii</sup> Expressed counterfactually, it can be said that without palliative care, patients and families would be exposed to unnecessary levels of avoidable suffering during illness and post-bereavement. What is more, palliative care is said to be an affordable and cost-effective intervention for health care systems.<sup>xliv</sup> Medications such as morphine are relatively cheap<sup>xlv</sup> and the introduction of palliative care often coincides with the cessation of curative treatments which are expensive and often continued long after they may be expected to be effective. Significantly, the resources needed in order to deliver palliative care are said to be affordable, which supports suggestions that is a feasible mode of care in all resource contexts and that its availability should not be constrained for financial reasons in any world setting.<sup>xlviii</sup>

### **Global need for palliative care**

In spite of demonstrable benefits to patients living with serious illnesses and their families, palliative care has been fully integrated into health systems in only 45 of the World's 234 countries.<sup>ii</sup> In 75 countries, there are no known services at all. This is of concern as in recent times arguments have been constructed to suggest that in circumstances where no pain or palliative care services are available, the severity of suffering which patients suffer is akin to being physically tortured.<sup>xlvi</sup> This argument has been made by activists to suggest that as palliative care has been shown to reduce suffering, that the failure of nations to provide palliative care puts them in breach of human rights law, which guarantees citizens to be free from "torture, inhuman or degrading treatment [United Nations, 2015]"<sup>xlvii</sup>.

In 2014, the WHO estimated that globally, 20 million people were living with illnesses which require palliative care, based upon an assessment of *end of life* need.<sup>xlviii</sup> Within this population, the vast majority were adults, 69% of which were over 60 years old which supports suggestions that as populations age, palliative care need increases. Children living with serious illness are said to represent 6% of the global need for palliative care. These figures are based upon the need for palliative care if it is introduced after curative efforts are ceased. Therefore, if people living with a diagnosis of a serious illness who would benefit from the introduction of palliative care alongside curative efforts, but are not close to the end of life, these numbers increase to over 40 million. In

this regard, it is notable that the vast majority of palliative care need is in low and middle income countries where there has been limited development of palliative care [Figure 1].

**Figure 1: Distribution by WHO regions of rates of global need for palliative care at the end of life**



Source: World Health Organization, 2014<sup>xlviii</sup>

What the map in Figure 1 does not show, is global need in relation to current service provision. China, for example, is known to have the highest gap between need and availability of services<sup>xlix</sup> and there are few palliative care services in Francophone countries in Africa.<sup>l</sup> Additionally, the WHO estimates that the need is more than doubled if family members of people who may benefit from palliative care are included, pushing estimates of global need towards 100 million people annually.<sup>xlviii</sup>

In addition to this, the world's population is both growing and ageing, which in real terms means an increase in the total number of people who live and die from serious and chronic illnesses who may benefit from palliative care.<sup>li</sup> Furthermore, increased survival periods of children and adults living with serious illnesses have led many people to live long lives after being diagnosed. Advocates argue that this has led to people living with increased co-morbidities during illness which has further increased the need for palliative care.<sup>lii</sup> Furthermore, global successes in reducing deaths by infectious diseases, has seen the burden of long-term non-communicable diseases increase.<sup>liii</sup> In richer nations, where life expectancy is high, the need for palliative care has been further increased due to the new public health crisis posed by illnesses such as dementia.<sup>liv</sup> The burden of dementia and other age-related illnesses is also likely to further increase as life expectancies continue to rise in low and middle income countries.<sup>lv</sup>

## Impact of global ageing

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.<sup>lvi</sup> 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.<sup>lvii</sup> This challenges both the capacity and sustainability of 'health systems' which within this study are understood as:

The combination of resources, organization, financing and management that culminate in the delivery of health services to a population [2007].<sup>lviii</sup>

Many palliative care services exist outside of the formal 'health system' and operate independently from national health initiatives, with funding from charitable and philanthropic organizations.<sup>lix</sup> Using the above definition allows the inclusion of 'palliative care' within discourses of 'health systems strengthening' and also incorporates public and privately funded systems. Distinctions will however be drawn where appropriate when palliative care services operate outside of any national-level funding streams or strategies, with 'integration' into national health policies a key challenge to the field.

As suggested above, modern medical practices often follow technical – and expensive – approaches to the treatment of illness, often beyond a stage where curative efforts are likely to be effective.<sup>lx</sup> As such, global ageing has become a key area of health systems development in terms of health expenditure, as health systems face increased demand and consequent threats to their sustainability.<sup>lxi</sup> This circumstance benefits neither patients who undergo futile and distressing treatments nor health systems which incur high costs unnecessarily.<sup>lxii</sup> In this regard, palliative care is said to become the most effective intervention for improving the quality of life of patients and what is more, is said to be a relatively inexpensive intervention, which may reduce costs to healthcare systems.<sup>lxiii</sup>

In spite of such potential benefits, global ageing policies have not prioritised the further rolling out of palliative care services. The current response from global organizations such as the United Nations (UN) and the WHO to the 'problem' of global ageing has centred round the promotion of 'active and

healthy' ageing. Policies such as WHO's Framework for Active Ageing aim to increase wellbeing in older people as well as reducing health systems costs through decreased usage.<sup>lxiv</sup> However, in spite of many studies demonstrating a link between illness, death and household poverty<sup>lxv</sup>, 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 the developing world cannot afford<sup>lxvi</sup>, attention to the financial aspects of illness and bereavement appears warranted.

### **Palliative care in global health discourse**

Until recently, palliative care had received little attention within global health policies. However, in 2014 the palliative care community had cause for optimism that the discipline was receiving greater attention when the World Health Assembly (WHA) passed a Resolution which called upon national governments to "[strengthen] palliative care as a component of comprehensive care throughout the life course".<sup>lxvii</sup> The proposition passed unanimously, with all member states of the WHA ratifying the Resolution. Significantly, the Resolution placed the obligation to increase palliative care provision firmly upon national governments.

It may be suggested, however, that in order for the Resolution to be implemented internationally, that support from global actors is likely to be required. Different International Organizations (IOs) operate in different ways to impact upon health issues at national level. A detailed overview of the roles of different International Organizations (IOs) and other health actors is presented in Chapter Three. Here, however it suffices to draw a conceptual difference between 'normative' and 'funding' agencies. Funding agencies such as the World Bank, funded themselves by member countries, have the legal and financial power to fund and implement health projects directly.<sup>lxviii</sup> Therefore, they are able to implement their policies and strategies with nations without relying upon national governments to finance projects. Alternatively, the role of normative agencies such as the WHO is to provide leadership, set norms and standards and provide technical assistance to governments for the improvement of health.<sup>lxix</sup>

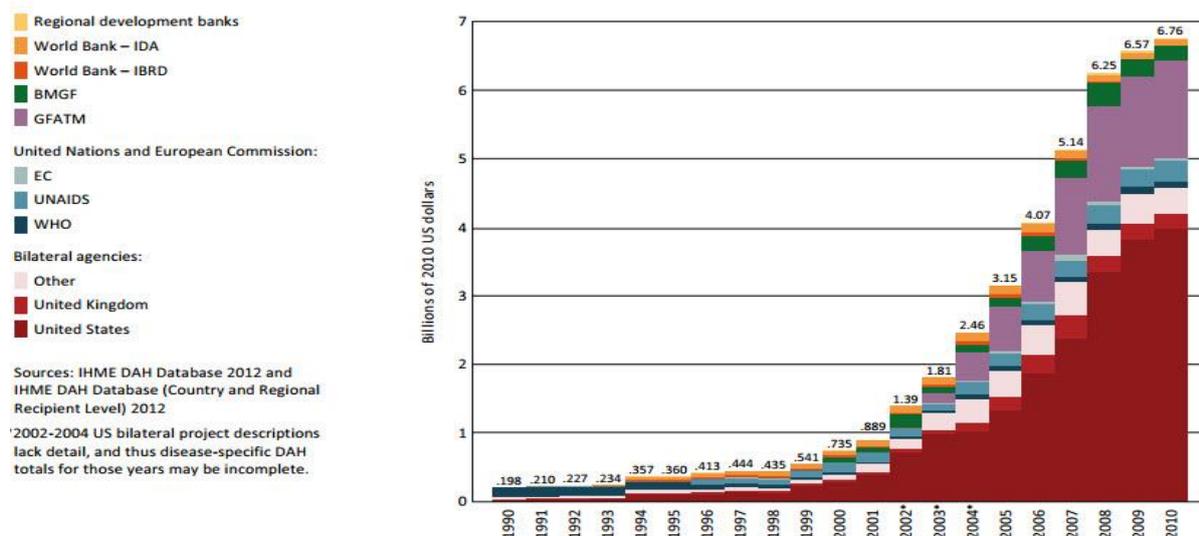
The WHA Resolution for palliative care therefore, may be considered an important political statement, placing palliative care formally on the global health agenda. However, the absence of funding to implement palliative care and meet these 'standards' means that the Resolution places the financial responsibility for its implementation solely upon national governments. This is

significant as many national governments operate within contexts of resource scarcity and many health systems worldwide are underfunded, even without additional responsibilities to introduce palliative care services.<sup>lxx</sup>

The current absence of any global funding agency involvement in the implementation of the Resolution is therefore of concern as attention and prioritisation by global-funders holds the potential for major new sources of finance for governments, particularly of low income countries, to implement health projects.<sup>lxxi</sup> By way of example, Figure 2 shows the increase in Development Assistance for Health (DAH) funding for tackling HIV/AIDS following prioritisation of the issue within the Millennium Development Goals (MDGs).

**Figure 2: Development Assistance For Health (DAH) for HIV/AIDS by channel of assistance, 1990-2010**

DAH for HIV/AIDS by channel of assistance, 1990-2010



Source: Humanosphere, 2013<sup>lxxii</sup>

This Figure demonstrates that national health financing comes not only from within nation states, but that global actors such as the World Bank contribute a high amount of resources. Additionally, a large amount of development financing occurs bilaterally, with richer nations such as the United Kingdom (UK) and the United States (US), providing development aid to subsidise health projects directly in other nations.

HIV/AIDS was prioritised within the MDGs over and above other health problems in spite of representing the highest burden of disease in Sub-Saharan Africa only.<sup>lxxiii</sup> This suggests that

priorities at global level are not formulated solely upon the scale of health problems. For instance, at the inception of the MDGs, non-communicable illnesses such as cancer represented the highest global burden of illness, but addressing such conditions was not included as a global health priority. Therefore, if policy priorities are not based solely upon need, how then do certain issues come to receive more policy attention than other worthy claims?

One explanation for why certain issues become prioritised over and above other valid claims suggests that issues receive attention based upon how a problem is ‘framed’. Boas and McNeill argue that actors such as powerful states, powerful organizations and even powerful disciplines ‘frame’ issues:

[Which] serves to limit the power of potentially radical ideas to achieve change...[and] makes favoured ideas seem like common sense, and unfavoured ideas as unthinkable [2004.p.2].<sup>lxxiv</sup>

Many health issues can be ‘framed’ in different ways. For instance, the HIV/AIDS epidemic has been presented in many guises, for instance, a national security issue,<sup>lxxv</sup> a human rights breach<sup>lxxvi</sup> and a development (economic) limiter.<sup>lxxvii</sup> Different ‘frames’ are presented by different actors and hold the potential to influence and appeal to other actors in line with their own agendas. We see this in the differing presentations of the HIV/AIDs crisis as a human rights issue from the WHO (a normative agency) and as an economic issue from the World Bank (a financial institution).

In this regard, palliative care is a health issue which has not, as yet, ‘framed’ itself successfully in order to receive attention within global health discourses. It follows that there is no specific health goal contained within the forthcoming global development priorities, the Sustainable Development Goals (SDGs),<sup>lxxviii</sup> that contains an indicator to measure palliative care development. This suggests, that in spite of the WHA Resolution, palliative care continues to develop outside of global health priorities.

There are however, opportunities for palliative care to develop further within Goal 3 of the SDGs as part of the target to achieve Universal Health Coverage (UHC).<sup>lxxix</sup> Furthermore, the Worldwide Hospice and Palliative Care Alliance (WHPCA) has been recognised as a ‘voluntary partner’ within the Goal, charged with implementing the WHA Resolution. However, whilst the WHPCA - like the WHO – is able to offer technical assistance to governments, they do not have the resources to fund projects.

Additionally, the absence of an indicator for palliative care development within the Goals means that any progress will be difficult to measure. Finally, the absence of a palliative care indicator suggests that it is not a priority issue and that any funding which is allocated towards meeting the SDGs is unlikely to be targeted towards incorporating palliative care as part of UHC.

This study therefore emerged to examine the apparent disconnect between the severity of the global need for palliative care and the importance which global policymakers ascribe to the issue. The overall aim of this thesis is therefore to consider if, and how palliative care can more successfully situate itself as part of broader global health priorities as an international development issue. However, before presenting the methods employed in order to address this question, it is first important to consider what is known about how palliative care has developed internationally. If global leadership has not (as yet) driven development, how has the practice of palliative care spread from its first articulation in the 1960s to exist in all world regions?

### **What is known about how palliative care has developed internationally?**

It is well documented that palliative care (as we now understand it) was pioneered in the UK by Dame Cicely Saunders and that it spread to the United States through the work of Saunders as well as that of another pioneer, Dr. Elisabeth Kubler-Ross<sup>lxxx</sup>. More recently, this narrative of ‘pioneer-led development’ has been added to by the work of Anne Merriman, who is credited with introducing palliative care to Singapore in 1985<sup>lxxxii</sup>, as well as establishing Hospice Africa in Uganda in 1993. The service in Uganda is significant as it is now considered a model of care for the rest of Sub-Saharan Africa to follow<sup>lxxxii</sup>. Another study explains the origin of palliative care in Japan as being “brought from England” [2010.p.4].<sup>lxxxiii</sup>

These pioneer-led narratives are reflected in a 2006 study conducted by the International Observatory on End of Life Care (IOELC) which represented the first global scoping exercise of global palliative care provision.<sup>lxxxiv</sup> The study was updated in 2011 by the Worldwide Palliative Care Alliance (WPCA) however, the 2006 report contained broader analysis of palliative care development and will be the focus here.

The study identified 16 factors that they suggest are reasons for what they term the rapid international growth of palliative care provision. The methods used to identify these reasons will be

critiqued later in the chapter, but firstly, their findings regarding factors which have driven development are presented in Table 1.

**Table 1: Factors influencing the development of palliative care services**

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• The emergence of palliative care champions	• Support from volunteers
• A desire to provide better care for the dying	• Good patient and family experiences
• Freedom from pain being viewed as a human right	• Better access to education and training
• The growing awareness of new possibilities	• Strategic planning and implementation
• The practical needs of an ageing population	• Changes to the laws governing opioids
• A changing political climate (within the Council of Europe, for example)	• Leadership initiatives are having an effect on policymakers
• Advocacy has become sharply focused	• Improved communication systems give easier access to information
• Funding has become available.	• Broader support networks are becoming established

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Source: Wright M et al. IOELC, 2006.<sup>lxxxiv</sup>

Aside from ‘freedom from pain being viewed as a human right’, these ‘reasons’ are difficult to generalise with international relevance. For example, whilst ‘changes to the laws governing opioids’ may have assisted the development of palliative care in certain countries such as the US,<sup>lxxxv</sup> barriers continue to exist in others (e.g. Russia<sup>lxxxvi</sup>) and even differentially within countries (e.g. India).<sup>lxxxvii</sup> The authors make sense of these variables through discussion of two scenarios of palliative care development; ‘top down’ and ‘bottom up’ models:

The ‘bottom up’ model is characterised by an energised group of activists identifying local need and deciding to meet it...

...The ‘top down’ model is where the Ministry of Health becomes involved at an early stage and, in collaboration with clinicians, policy-makers, the House of Insurance, and other partners, sets in train the strategic and legislative procedures to incorporate palliative care

into the national health system of the country [Lynch et al, 2006. P40].<sup>ii</sup>

Certainly, there are examples to fit this analysis. In India, for instance, the ‘Kerala model’ – now a WHO Demonstration project - was a community movement, which led to the adoption of state, then national-level palliative care policy development in India.<sup>lxxxviii</sup> Furthermore, this community-led approach is said to offer a potential model for other low-resource settings to follow in terms of increasing access to palliative care.<sup>lxxxix</sup> By way of contrast, a study focussing upon developments in Latin America points to; health policy, established plans based on needs assessments and interaction with primary care as key determinants of palliative care programs.<sup>xc</sup> That is, development factors which are driven more from national policymakers, or a ‘top down’ approach.

On a global scale, the factors influencing palliative care development presented by the 2006 study are difficult to quantify [Table 1]. Although the IOELC report their data collection methods, it is not clear which of these explanatory factors of development apply to which countries, nor is it suggested that these factors are present in each country in which palliative care has developed. The 2006 study did take some tentative steps to engaging with macro-data relating to socioeconomic factors reporting data on; Human Development Index (HDI) rankings, Gross Domestic Product (GDP) per capita, Crude Death Rates (CDR), and Population in relation to country groupings of palliative care development. The data were however, presented only descriptively. Although they claim that a “strong correlation between palliative care and human development [p40-1]”, only the percentage of countries in each category in relation to their Human Development Level are reported and no correlations are demonstrated [Table 2].

**Table 2: Palliative care and Human Development, by group**

	Total countries		High development		Medium development		Low development		No HDI	
	N	%	N	%	N	%	N	%	N	%
Group 4 countries	35		29	83	5	14	1	3	0	0
Group 3 countries	80		20	25	41	51	7	9	12	15
Group 2 countries	41		6	15	23	56	8	20	4	10
Group 1 countries	78		2	3	19	24	15	19	42	54

Source: Lynch et al, 2006<sup>lxxxiv</sup>

Criticism of the study’s statistical methods aside, the data does appear to show an association between level of palliative care development and level of human development. A further look at the

country classifications in 2011 in relation to Human Development, finds that of the 20 countries who had achieved advanced integration into the mainstream health system<sup>xci</sup>, 17 of those countries also achieved a rating of Very High Human Development in 2011.<sup>xcii</sup> This apparent association warrants greater statistical scrutiny and raises further questions regarding which other structural factors may have had an influence over palliative care development.

Additional concerns have, however, been raised regarding the subjectivity of the country group classifications themselves and the methods used to determine rankings.<sup>xciii</sup> Country rankings were determined with a mixed-methods approach drawing data from:

Published articles in peer reviewed and professional journals, books and monographs, palliative care directories, palliative care and related websites, data provided by the EAPC Task Force for the Development of Palliative Care in Europe, IOELC reviews and databases, as well as gray literature and conference presentations [2013. p.1096].<sup>xciv</sup>

In addition to this, where possible, ‘key experts’ within countries were consulted and asked to reflect on the level of development in their country. Where this was not possible, rankings were agreed between the authors. Both of these methods are problematic due to their subjectivity, risks which are acknowledged by the authors. Experts can be a valuable source of data. However, there is an inherent risk of information bias when consulting experts, responses risk being over-emphasised to reflect the opinion of the expert either to overstate achievements or underestimate failings.<sup>xcv</sup>

Further, that the authors applied their own country rankings in the absence of key experts based on differing available data, raises questions regarding the objectivity of the rankings and their resulting comparability. Furthermore, experts who were identified, were asked to reflect upon phrases such as “the development of a critical mass of palliative care activism in a wide range of locations [p.4]”<sup>xcvi</sup> to determine their own ranking, though no guidance is given on how this can (and should) be quantified which leaves the rankings open to further critique regarding their subjectivity.

In addition to preliminary efforts to map the global development of palliative care, 2010 saw the publication of the first global ‘Quality of Death index’ by the Economic Intelligence Unit (EIU).<sup>xcvii</sup> Forty countries were included in the ranking system, which was based upon ranking weighted indicators across four domains; Basic End-of-Life, Healthcare Environment, Availability of End-of-Life Care, Cost of End-of-Life Care and Quality of End-of-Life Care. To some extent, the findings echoed

those of the WPCA study, with the UK ranked as having the highest quality end of life care, with other countries within the top ten concentrated in high-resource settings.

The index was updated in 2015 with 80 countries included in the index and the UK maintaining its place at the top of the rankings.<sup>xcvii</sup> Whilst the top ten is once more dominated by countries from high-resource settings, the updated study reported significant progress in the Asia-Pacific region in terms of accelerated development of high quality of care. However, in spite of some corroboration between rankings between the IOELC and the EIU reports, some discrepancies are a cause for concern, which may in part be attributed to the subjectivity of ranking methods and a lack of clarity regarding how to measure 'high quality' palliative care. For instance, the EIU study in 2010 used a 10-point scale, on which the United Kingdom achieved first place in the rankings (in line with its Group 6 status), however, other countries such as Uganda were classified quite differently between the studies. Despite being allocated to the highest available category in the WPCA study, Uganda was scored only 2.1/10 by the EIU and occupied 39th place out of 40 in the quality ranking. This ranking places Uganda behind Mexico in terms of quality of palliative care provision, a country which was categorised by the WPCA as having only 'isolated palliative care provision'. These discrepancies urge caution when using both the WPCA and EIU datasets, however, they remain the only known global projects to map development and assess quality of palliative care respectively.

Instances of countries which are said to have developed palliative care services to a high level are present in all regions of the world. However, if, as has been suggested, there are different models of palliative care appropriate for all resource contexts<sup>xcviii</sup>, why are high levels of service development so concentrated in the developed world? Suggestions that 'bottom-up' or community led approaches to development as seen in Kerala are replicable in other settings have not been accompanied by discussion of the challenges of fostering community engagement in health issues through policy.<sup>xcix</sup> Furthermore, although national governments have been identified as being potentially key influences over development, existing narratives do not place palliative care within broader global health discourses of development.

This circumstance raises important questions regarding what the role of global actors should be in the further development of palliative care. Emphasis upon 'model services' which are 'context specific' is suggestive that few of the challenges that nations face with regards to implementing palliative care are 'shared'. This question of 'what issues in palliative care are universal?' is one which runs through this entire thesis. Can policies which are formulated at global level translate to

person-centred care at the individual level? Additionally, as palliative care development has shown to occur largely due to the transfer of ideas and practices *between* nations, rather than from the national implementation of policies made at global level, what is the importance of global level actors for the future development of palliative care? The extent to which palliative care research has engaged with such issues is, however, unknown and existing narratives of development remain largely descriptive, with little application of theoretical perspectives of global policymaking processes.

This thesis will demonstrate that strengthening the relationship between national level palliative care actors and existing global stakeholders such as the WHO is of extreme importance. This is based upon the potential held by global health actors to greatly accelerate the development of health care issues. Consider for instance how the Ebola outbreak in West Africa was tackled in 2014. Faced with a new health challenge, low income nations such as Sierra Leone, with developmental health care systems, did not have the capacity to contain the threat.<sup>c</sup> It was therefore, the intervention of international and global health actors, interceding to assist government responses which led to the roll-back of Ebola.

We may understand the obligations placed upon national governments by the WHA palliative care Resolution in a similar way. Palliative care has only relatively recently been expressed as an area of need. Therefore, it is has been placed on top of existing healthcare challenges in nations where health systems are weak and life expectancies are low. Moreover, in such circumstances palliative care services are generally not present and the approach to care is not well understood. Richer countries also face challenges in further developing palliative care, where need continues to increase and the focus shifts from providing a basic level of care to improving quality of care, for instance in the Netherlands.<sup>ci</sup>

It is therefore clear that new approaches and new resources are required in order to advance palliative care development. Engagement by the palliative care community with *new* global institutions – most particularly funding and regulatory agencies – is vital in order to facilitate the global development of palliative care. Yet, as will be shown, an apparent reliance upon framing palliative care as an international human rights issue may not be a strategy which is likely to engage with global funding agencies. This thesis therefore seeks to answer the following research question:

*Can the global development of palliative care be furthered through increased understanding of global policymaking processes and the presentation of palliative care as an international development issue?*

Answering this question, may help palliative care capture the attention of a wide range of new stakeholders and attract new sources of funding. Moreover, increased understanding of the importance of palliative and its wide reaching benefits may ensure that it is included as a fundamental aspect of the new global health priority of achieving Universal Health Coverage.

## **Conclusion**

It has been shown in this chapter that there is a demonstrable global need for palliative care. Millions of people each year continue to endure high levels of suffering caused by serious illness without receiving appropriate pain treatment and care during illness and at the end of life. Palliative care has been shown to be effective in vastly improving the quality of life of people living with serious illness and their families. Although the concept of palliative care was only developed in the 1960s, services now exist in 136 of the world's 234 countries. However, worldwide there remains a significant gap between demand and supply of palliative care services. Moreover, as the world population both increases and ages, it has been shown that the need for palliative care will increase further. Yet, serious challenges exist to the further development of palliative care services and essential medicines for palliative care such as morphine continue to be prohibitively regulated at both national and global levels.

Existing narratives of palliative care development focus upon processes which occur within nations and have been shown to lack theoretical insight with regards to global policymaking processes. Such characterisations have rarely located development within the broader landscape of global health governance which in part reflects the historical disengagement between global level and palliative care actors. However, new global attention for palliative care in the form of a 2014 WHA Resolution calling upon governments to integrate palliative care into health systems has raised hopes for an acceleration of palliative care development based upon globally-set norms and standards. The Resolution may be considered an important political statement in recognition and promotion of palliative care. Seen more broadly however, it also places new healthcare responsibilities on governments and already financially-strained health systems. Whilst health systems in all world contexts face serious budget pressures, the Resolution does not contain any financial backing in

order to implement its terms. Moreover, awareness of palliative care worldwide remains low and serious action is required to ensure that the Resolution is implemented and does not remain an aspirational statement.

This thesis considers the opportunities presented by increased understanding of and engagement with global health policymaking processes to consider palliative care an international development issue. Significant funding opportunities are potentially available from important global health actors such as the World Bank. However, to date, palliative care does not yet appear to have 'framed' itself as an issue of developmental importance to global funding agencies.

Before moving on to set out the methodological approach [Chapter Four], it is important to examine how a Global Social Policy approach identified in this chapter can enrich understanding of palliative care development to date within the global governance landscape. By doing so, key challenges and opportunities for the further development of the field are identified. Further sub-research questions are also generated in terms of how and why palliative care as a neglected healthcare issue may be able to achieve policy prioritisation.

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## **Chapter Three**

# **Towards a Global Social Policy Understanding of International Palliative Care Development**

## **Introduction**

In response to current research and development narratives which have often viewed palliative care as an national issue in isolation from other global healthcare priorities (as identified in Chapter Two), this chapter seeks to situate palliative care within the context of processes of international and global healthcare development. As such, it looks beyond existing palliative care literature, towards a theoretical understanding of global policymaking processes offered by the Global Social Policy (GSP) school of thought.

GSP seeks to understand how policies are formed and why certain policy issues are prioritised over and above other equally valid claims. Moreover, GSP scholars acknowledge that there has been a shift from social policy formulation taking place almost purely at national level towards a system where a high degree of influence over national social policies is exercised by global level actors.<sup>i</sup> That is, that there has been a globalisation of economic, social and political issues – with the health sector a key element of this.

It is therefore appropriate to begin this chapter, by considering how this shift to global-level policymaking has occurred and been influenced by forces of globalisation, as well as to identify the key actors operating at global level to influence healthcare policy. The following section therefore reviews how globalisation has presented new challenges in terms of health policy as well as impacting upon the autonomy of nation-states to determine policy. Following this, key actors in global health are identified with discussion regarding their relative power to influence and implement policies within nations of all world settings. Where appropriate key challenges and opportunities for the further development of the field of palliative care within a globalised world, are considered.

## Globalisation and health

Global Social Policy scholars suggest that the global level has seen a wide range of state, non-state and private actors emerge to operate within what has been termed a “contested terrain of global governance [2007.p.15]”.<sup>ii</sup> It has been argued that this globalisation of governance has impacted upon the capacity of states to act in the interests of their citizens. In terms of healthcare, Richard Dodgson et al [2002] suggest that processes of globalisation have impacted upon the power of national governments to act autonomously in the interests of the health of their populations in four key ways.<sup>iii</sup>

Firstly, it is argued that globalisation has increased trans-border health risks. For instance, the potential for the spread of infectious diseases between nations is increased due to higher levels of international travel and migration.<sup>iv</sup> Additionally, air-borne diseases such as malaria pay no respect for international borders and provide international threat. To understand palliative care in these terms is, however, challenging and scholars do not appear to have engaged with and understood palliative care in a globalised world. Due to high symptom burdens, seriously ill palliative patients are often forced to be sedentary.<sup>v</sup> Moreover, whilst people carrying transmittable illnesses can and do cross borders, such occurrences are not conceptualised as a communicable threat based upon their palliative care needs. Furthermore, no examples of research studies are known to have identified palliative patients crossing borders as part of ‘medical tourism’ in order to access palliative care. Instead, more notable have been instances of people travelling internationally in order to receive an assisted death, a phenomenon seen predominantly between countries which *both* have palliative care services. For instance, people travelling from the United Kingdom (UK) where assisted dying is illegal, to Switzerland where it is permitted.<sup>vi</sup>

Secondly, as referred to above, the emergence of non-state actors at global level has served to limit the relative influence which national governments are able to exert in response to globalising forces which affect basic determinants of health.<sup>ii</sup> In this regard, the distinct roles of state and non-state actors have become blurry in terms of activities such as agenda setting, resource mobilisation and allocation and dispute settlement.<sup>vii</sup> One consequence of this has been that through trade laws, the interests of powerful private sector actors have been protected, which limits the potential for nation-states to implement policies which impact upon private profits. A recent example from Uruguay illustrates this, where Phillip Morris, the transnational tobacco company, successfully sued the government for its restrictive smoking laws introduced to promote public health.<sup>viii</sup>

It may be suggested that private entities such as pharmaceutical companies, have vested-interest in a biomedical model which promotes expensive curative treatments over relatively cheap medicines for palliative care.<sup>ix</sup> This circumstance therefore represents a barrier to palliative care, which promotes a cognitive shift away from overly-medicalised approaches to the treatment of illness.<sup>x</sup> However, whilst palliative medicines are often inexpensive, the need for them is prevalent and set to increase.<sup>xi</sup> On this basis, it is of concern that the palliative care community does not yet appear to be engaging with the pharmaceutical industry as a potential partner. Profits margins may be smaller for palliative medicines when compared with other treatments, however demand dictates that the pharmaceutical industry will have an interest in supply.<sup>xii</sup> Moreover, the pharmaceutical industry is a present reality and in this regard, the potential for the private entities to lobby alongside palliative care activists for the de-regulation of opioid medications warrants attention which it does not yet appear to have received.

Thirdly, forces of globalisation have been shown to be associated with the sustenance and widening of socioeconomic, political and environmental problems.<sup>xiii</sup> For instance, neoliberal policies have been shown to widen the income gap both within and between nations.<sup>xiv</sup> From the 1980s, policies of structural adjustment saw loans being made to nation-states to fund healthcare, with conditionalities that healthcare services would be privatised in order to secure funds.<sup>xv</sup> Once more, such policies served to limit the capacity of states to act in their own interests, with additional concerns regarding the potential of private systems to increase inequality in terms of access to healthcare services.<sup>xvi</sup> With palliative care services currently concentrated in high income countries, this circumstance raises concerns that should global funds be accessed by low and middle-income countries for palliative care, that they may be obliged to use such funding to develop private services. Therefore, access to such services may become predicated on capacity to pay for care, a situation which would run counter to public health recommendations for palliative care development.<sup>xvii</sup>

Finally, globalisation has contributed to a reduction of the political and practical capacity of governments to respond to global health challenges in several key ways; for instance again in terms of the availability of essential medicines. In 1995, under the administration of the World Trade Organization (WTO), the Trade-Related Aspects of Intellectual Property Rights (TRIPS) became international law and allowed pharmaceutical companies to patent pharmaceutical processes and products for 20 years.<sup>xviii</sup> Identified above was a potential role for pharmaceutical companies to promote palliative care interests through de-regulation of opioid medications. However, such trade laws urge a note of caution when regarding the pharmaceutical industry as a potential ally for

palliative care. That is, de-regulation would place no obligation upon companies to provide *cheap* medicines and indeed more expensive medicines such as patented fentanyl patches are more profitable.<sup>xix</sup> Therefore, there is a risk that companies may only make profitable medicines available, which would further accentuate socioeconomic inequalities of access to healthcare identified above.

Such issues will be returned to in a subsequent section of this chapter which focusses upon the influence of Transnational Corporations (TNCs). However, in order to understand the complex relationships and interactions between important global actors as well as national governments, it is appropriate to first consider who the key actors in global health are, their primary mandates, as well as their relative power to influence policies in national settings. On this basis, the following section presents a brief overview of how globalisation has seen new actors in global healthcare policymaking making emerge.

### **A brief history of global health governance**

The shift of healthcare governance from operating solely at the national level, which saw new global actors emerge to influence health care policy internationally, is not a purely modern phenomenon. However, the twentieth century saw processes of globalisation accelerate exponentially.<sup>ii</sup> International Organizations (IOs) emerged, funded by member states, but operating outside of national jurisdictions<sup>xx</sup> In Chapter Two, a conceptual difference was drawn between different IOs. Normative agencies, such as the World Health Organization (WHO), whose primary role may be considered 'agenda setting' and funding agencies, for example the World Bank, which have the resources required to directly implement policies and practices within nations in line with their own development mandates. Here follows, a brief discussion which provides further detail regarding the roles and influence of these different global actors in terms of how they wield influence over national health policies and practices.

#### **Normative agencies**

Normative agencies such as the United Nations (UN) in 1945 and the WHO in 1948 emerged in order to address new and pre-existing global challenges relating to social issues including: human rights economic development, education and health.<sup>ii</sup> Within such organizations, member-states formulate global guidance and issue policies through global resolutions, conventions and regulations in response to perceived areas of global need. Such policies are agreed at the global level by member

countries from all resource contexts, meaning that all nations aspire to the same standards in spite of different levels of resource availability. Nation-states must also formally ratify resolutions and conventions in order to be bound by their terms. However, although ratification does leave countries subject to international law, enforcement mechanisms at global level are underdeveloped, and few individuals or organizations are ever criminally prosecuting for violating the terms of their international agreements. For example, the United Nations Convention on the Rights of the Child (UNCRC) issued in 1989 has been ratified by 196 countries, however prosecutions for violating the terms of the agreement are rare, despite many cases of known violations of this treaty.<sup>xxi</sup> In this sense, such policy types may be considered ‘aspirational’.<sup>xxii</sup>

A notable exception, however, of a convention which *does* have a formal enforcement mechanism is the 1961 Single Convention on Narcotic Drugs which continues to be implemented by the International Narcotics Control Board (INCB).<sup>xxiii</sup> This is significant for palliative care, as the INCB is the international regulator for opioid medications such as morphine. In this regard, due to the high prevalence of governments which continue to restrict their use, the INCB has faced severe criticism for restricting morphine as a ‘narcotic drug’, rather than enabling access as an ‘essential medicine’.<sup>xxiv</sup>

However, more usually, conventions and resolutions including the WHA Palliative Care Resolution are not formally enforced.<sup>xxv</sup> Indeed, whilst normative institutions such as the WHO and other UN agencies have important leadership roles to play in terms of setting global norms and standards, they are not able to implement policies directly within nations and rely upon their policy recommendations to be adopted voluntarily by nation states.<sup>xxvi</sup> This is of concern as identified in Chapter Two, as developmental healthcare systems desperately require new sources of financing for palliative care if they are to implement the Resolution. In this regard, attention now turns to global funding agencies, institutions which do hold the financial power necessary to implement policies and practices of their own design within nations.

### **Global funding agencies**

The 1980s saw the emergence of International Financial Institutions (IFIs) such as the World Bank and the International Monetary Fund (IMF) as powerful actors in global health policy.<sup>ii</sup> Like the UN, both institutions are also funded by member-states. However, in contrast such organizations to normative agencies which focus on health as a human right, the IFIs largely consider good health as a

mechanism for the delivery of their primary objectives of poverty alleviation and economic growth.<sup>xxvii</sup> The following quote from Jim Yong Kim, the current president of the Bank is illustrative:

To promote inclusive growth, the World Bank Group works to facilitate the diffusion of knowledge and support countries in investing in the productivity and skills of their people [2014].<sup>xxviii</sup>

This speech, delivered in 2014 to articulate the Bank's ongoing strategy for international development is notable as it adopts a 'human capital' approach to the furthering of health and includes no mention of human rights. Moreover, it is consistent with what has been the historic approach of the Bank to international development, that the lives of everyone are improved through overall economic growth.<sup>xxix</sup> Therefore, primarily global funding agencies disburse funds and implement programs within low and middle income countries. However, this emphasis upon economic interest, rather than human rights would appear to limit the opportunities for palliative care to engage with such organizations, as current advocacy efforts focus upon the presentation of access to palliative care as a human right.<sup>xxx</sup>

A further distinction between the IFIs and normative agencies is that they are able to implement their policies directly. A common mechanism of doing so has been through conditional loans.<sup>xxxi</sup> The approach of the Bank towards health development has centred around policies which aim to restrict public spending on welfare services and enable the involvement of the private sector in service delivery. This approach which was most prominent in the 1980s and 1990s but which continues today became known as one of *structural adjustment*.<sup>xxxii</sup> Under this model, countries are granted conditional loans to implement health projects, which are dependent upon the reduction of state involvement in healthcare delivery and the opening up of health systems to private providers and consequently, global markets.<sup>ii</sup> Once more, this appears to place such funding agencies in opposition to palliative care statements, which articulate a public health strategy for the development of palliative care.<sup>xxxiii</sup>

Although policies of structural adjustment have been severely criticised, as mechanisms of increased debt for low income countries as well as promoting societal inequality through decreased access to health and education services, they remain a key tool of the IMF and the World Bank.<sup>xxxiv</sup> For instance, Greece amidst financial collapse received loans from the IMF on the condition that austerity measures were implemented including drastic cuts to public health expenditure.<sup>xxxv</sup> The

measures are said to be decreasing access to essential medicines as well as increasing inequality of access to healthcare as private services emerge to meet demand, but on a pay-for-use basis. This demonstrates the ongoing neoliberal agenda of the IMF and that the global trend of privatisation of healthcare systems based upon global-level influence continues. However, the extent to which the increasing prevalence of privately delivered health services and the implications of this for palliative care is not well understood. It is therefore notable that within current narratives of development, such issues are not considered and palliative care development is often presented as being driven either by charitable and faith-based funding as well as publically funded models.<sup>xxxvi</sup>

In this regard, palliative care appears to have benefited to some extent from the rise of other another source of non-state health financing, global philanthropy.<sup>xxxvii</sup> Global philanthropy organizations disburse funding towards social issues and partners of their own designation, often through grants. Whilst palliative care does not appear to have received financing from other global funding streams, the Open Society Institute (OSI) funded the Project on Death in America which aimed to improve access to palliative care and promote compassionate care of the dying in the United States.<sup>xxxviii</sup> Additionally, OSI funded projects in Central and Eastern Europe, Asia and Africa through the International Palliative Care Initiative (IPCI).<sup>xxxix</sup> However, philanthropic funding is often short-term and OSI is unlikely to be able to promote the further global development of palliative care in isolation.<sup>xl</sup>

What then is the overall relevance for palliative care in understanding this global healthcare landscape? As presented, the primary role of normative organizations such as the WHO is to set standards, provide leadership and raise awareness of health issues. This was seen through the ratification of the palliative care resolution by the WHA. However, this global commitment remains a notional one and cash-strapped governments retain the responsibility for meeting their stated obligations. Yet, whilst IOs like the World Bank and the Global Fund distribute a vast amount of funding they have paid little attention to palliative care. Moreover it appears that any financing for palliative care from such institutions would only come, if it was presented as an issue in terms of the broader development strategies and policy priorities of global funders.

In this regard, a vast amount of funding was shown to be have been diverted towards tackling HIV/AIDS following its inclusion as one of the MDGs in Chapter Two. Where then does palliative care fit within global health priorities? To answer this question, attention now turns to past and current

global healthcare priorities in order to examine whether these have (or could) facilitate, or indeed limit, the further development of palliative care.

### **Global health priorities: Millennium Development Goals 2000-2015**

Between 2000 and 2015, the global health priorities focussed upon the agreement of eight Millennium Development Goals (MDGs).<sup>xli</sup> Although all goals may be considered relevant to health, three in particular were targeted at improving global health; reduced child mortality, improved maternal health and combatting HIV/AIDS, malaria and other (infectious) diseases. Significantly, none of these targets had mention of palliative care. Moreover, the focus upon infectious diseases moved attention away from non-communicable illnesses, which cause the highest proportion of need for palliative care.<sup>xlii</sup>

The establishment of the goals saw new commitment from national governments to providing 0.7% of annual national Gross Domestic Product (GDP) for international development.<sup>xliii</sup> Accordingly, a vast amount of financial resources were committed to attaining the MDGs by 2015 and the global health governance system was re-designed.<sup>ii</sup> New organizations emerged to disburse the vast amount of funds raised from donor countries, such as the Global Fund to Fight Aids, Tuberculosis and Malaria.<sup>xliv</sup> Also funded by member-states, the Global Fund differs from other IOs here inasmuch as funds are allocated in response to nationally devised plans, an approach which is said to be more aligned with national level needs and priorities. In this regard, conditionalities of funding placed upon countries relate not to how money should be spent, but upon the achievement of performance based targets.<sup>xlv</sup>

Although there has been significant progress in tackling infectious illnesses like HIV/AIDS<sup>xlvi</sup>, vertical financing for disease specific strategies had broader, negative consequences for national health systems. It has been argued that progress towards tackling such diseases through targeted interventions came at the expense of more holistic health systems strengthening which may have better incorporated palliative care.<sup>xlvii</sup> Furthermore, it is suggested that stronger health systems are more responsive to new healthcare challenges in that they “have the capacity not only to deliver interventions efficiently but also to sustain high levels of coverage, especially of the poorest and most vulnerable [2006.p87]”.<sup>xlviii</sup> In this regard, it is notable that existing narratives of palliative care development have not reported upon any benefits for palliative care based upon the outgoing MDGs and the vast amounts of financing which accompanied them.

## Global Health Priorities: Sustainable Development Goals 2015-2030

In 2015 the new globally defined priorities were agreed - the Sustainable Development Goals (SDGs) - which will shape global policymaking until 2030.<sup>xlix</sup> Of the 17 Goals, the most relevant to health is Goal 3 to 'Ensure healthy lives and promote well-being for all at all ages' which includes a target to:

Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.<sup>xlix</sup>

Achieving Universal Health Coverage (UHC) is a goal within which palliative care interests may more readily be advanced than through the disease-specific, targeted interventions which characterised the MDGs. Furthermore, the Worldwide Hospice and Palliative Care Alliance (WHPCA), has been included as a technical advisor in order to integrate palliative care into countries' health systems in accordance with the WHA resolution.<sup>i</sup>

However, it must be noted that there is no financial resources made available from either the UN or the WHPCA in order to fund the integration of palliative care. Additionally, the broadness of UHC as a goal necessarily means that decisions must be made regarding which areas of healthcare should be prioritised. The World Bank professes that development funding will need to increase from billions to trillions in order to meet the SDGs. Additionally, the World Bank favours a 'results-based financing' approach and in this regard, it is of concern that the Goals do not include an indicator for palliative care development.<sup>ii</sup> This is of particular concern to the palliative care community, due to the challenges of providing an evidence-base for palliative care identified in Chapter Two due to the complex array of potential inputs and outputs of palliative care as a complex intervention.<sup>iii</sup> Furthermore, it is not known the extent to which palliative care researchers are providing evidence in international context in terms of effectiveness and cost-effectiveness of interventions, a question which will be considered in Chapter Five.

IOs are likely to allocate funding for the attainment of the SDGs in line with their own organizational mandates. For instance, as suggested above, the World Bank is likely to fund projects health projects from a perspective of furthering human capital as opposed to human rights. However, IOs can be influenced in order to draw attention to neglected issues of international relevance. Accordingly, one characterisation of the broader aim of international to development is in terms of providing

'global public goods'.<sup>ii</sup> In this sense, whilst the policies of nation-states are implicitly focussed upon improving conditions within countries, global level actors may be considered to hold responsibility for issues which are shared between nations. What then are 'public goods' and could meeting the global need for palliative care provision be understood in such terms?

### **Global Public Goods**

Public goods are described as "goods that benefit all but which are not particularly in the interests of any one person to make and sell or any one consumer to buy [2007.p.121]."<sup>iii</sup> Street signs serve as a national-level example, as anyone can benefit from them and one person's usage does not diminish the benefit to others. Most commonly such goods are publicly funded as they benefit all and there is unlikely to be benefits for private companies.

At the global level, public goods are similarly non-rivalrous and non-excludable, but hold international benefit, for instance the eradication of infectious diseases, which cross borders and therefore represent an international threat.<sup>ii</sup> It follows, that to tackle such issues, international cooperation is required and it is suggested that sovereign states have become embedded within broader transnational forces in order to address such threats.<sup>iiii</sup> In this regard, the argument that transnational action centres around the provision of 'global public goods' appears to carry some weight. Especially when we consider the importance given to infectious diseases in the MDGs that prioritised the eradication of infectious disease such as HIV/AIDs and Tuberculosis which are not constrained by national borders and may therefore be considered 'shared threats'. However, it is too simplistic to consider that altruism is the sole determinant of global policies. Indeed, the notion of 'global goods' does not explain how other health issues, less easily defined as 'global goods'<sup>liv</sup> - such as reduction in child mortality have become global priorities.

In this regard it is difficult to conceptualise provision of palliative care as a global public good, as suffering which occurs due to illness is felt largely at the individual level and does not represent a trans-border threat. Furthermore, use of palliative medications reduces their supply and it cannot be said that the benefits of pain treatment are 'non-divisible', as one persons' use of medicines, reduces the overall supply. Whether this scenario should concern the palliative care community is unclear, because as demonstrated using the child mortality example, global attention has been shown to not *only* focus upon the provision of public goods as its mandate. It does however appear to preclude a 're-framing' of palliative care as a global public good in order to attract the attention of

policymakers. Therefore, the palliative care community must consider different ways in which palliative care can be presented as an issue of global need which is worthy of policy prioritisation.

What then, are the competing narratives for how and why policy is formulated at global level? In order to answer this question, it is important to consider two divergent understandings of both the role played by global level actors based upon insights from both World Society Studies and Global Social Policy (GSP). These two schools of thought are detailed below, however, to provide some context, a key difference in understanding centres around the questions of whether social policy issues should be considered in terms of their similarity or of their difference.

World Society theorists for instance emphasise the *similarity* of national social policies and institutions.<sup>iv</sup> That is, if we look at each country of the world, we will see schools, hospitals and other institutions which can be described as ‘world professional standards’. Alternatively, GSP theorists emphasise the *differences* between countries, for instance disparities in resources or why some countries have publicly funded health systems and others have privately funded systems.<sup>ii</sup>

On this basis, here follows a discussion of two schools of thought which represent each side of this competing and complementary debate, beginning with World Society Studies.

### **World Society Studies**

The starting point of analysis for World Society Theorists is to suppose that there is a pre-existing global society which transcends borders and transmits values, practices and institutions to nation-states through global cultural and associational processes.<sup>lvi</sup> Scholars such as John Meyer [1997], argue that nation states organize themselves around universalistic models and understandings of concepts, shared by global actors, such as citizenship, human rights and education. A key insight regarding the suggestion of social policy issues:

Rest[s] on claims to universal world applicability; for example, economic models of development and fiscal policy and medical models of the human body and health care delivery are presumed to be applicable everywhere, not just in some locales or regions [p.148].<sup>lvii</sup>

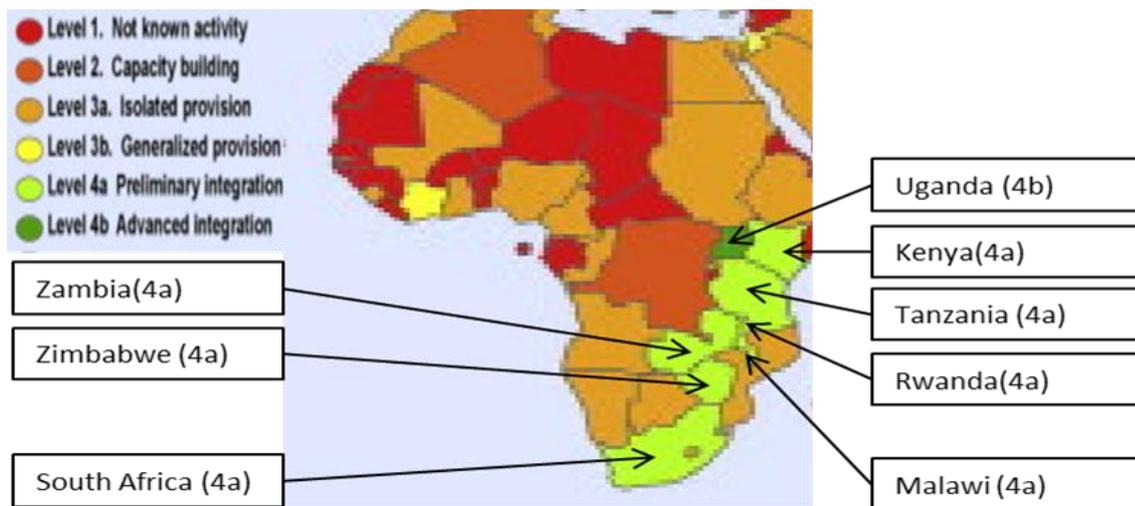
This analysis rests on the assumption that cross border associations act to spread policies and practices in line with these ‘universalistic models’. Through this natural diffusion of ‘agreed social norms and practices’ nation states become organized around a set of shared principles and institutions.<sup>lviii</sup>

In terms of palliative care, to follow this line of argument to its logical conclusion would be to suggest that there exists such ‘universalistic models’ of provision which require no adaptation to context and again raises questions regarding which elements of palliative care are ‘universal’. In line with ‘medical models of the human body’, it may be said that people worldwide experience pain similarly based upon ‘universal physiology’.<sup>lix</sup> However whilst there is some explanatory value in attempting to understand the world through universal truths and consensuses, this analysis feels glossy. There are many approaches to the delivery of palliative care – and even the universality of ‘pain’ is contested, with suggestions that cultural beliefs impact on individuals’ experience of pain.<sup>lx</sup> Nor does ‘universality’ account for the diversity of institutions and settings in which palliative care is delivered in spite of the existence of ‘hospices’ in all world regions.<sup>lxi</sup>

By characterizing fields such as healthcare as global institutions, World Society scholars are largely dismissive of the role of policy in the formulation and delivery of health and instead appear to characterize the emergence of organizations to deliver health services as inevitable. Indeed, Meyer points to the similarity of healthcare organizations between nations which, he argues “makes sense only of common world forces at work [2009.p.180]”.<sup>lxii</sup> This analysis is consistent with the concept of ‘policy diffusion’, whereby, when confronted with a challenge, policymakers observe the policy responses in other contexts and then respond similarly. That is, that “when confronted with a problem, decision makers simplify the task of finding a solution by choosing an alternative that has proven successful elsewhere [2008.p.841]”<sup>lxiii</sup>, through processes of policy learning.

This understanding of policy development identifies ‘geographical clusters’ of similar policies and practices which emerge from a policy genus that have apparent universal applicability. In this regard, there is some evidence that palliative care practices have converged in this manner, with the WPCA global mapping study identifying an apparent geographical cluster of palliative care development, emanating from Uganda [Figure 3]. Full detail of the constituency of country groups is presented in Appendix 3. It therefore serves here to note the concentration of ‘green countries’ in Sub-Saharan Africa, which have higher palliative care development and that orange, yellow and red indicate lower levels.

**Figure 3: Levels of palliative care development in Africa**



Source: WPCA, 2011<sup>xxxvi</sup>

However, what World Society Theory appears to not explain convincingly is *how* these institutions such as palliative care services come in to being or account for the differences between them. Furthermore, by characterising policy diffusion as a ‘natural process’ is to diminish the active roles played by ‘transfer agents’ such as Ann Merriman who is credited with introducing palliative care to Africa in 1990.<sup>lxiv</sup> Nor does a geographic analysis explain the high level of development of palliative care in a country such as Australia, which is geographically isolated from other countries that have successfully integrated palliative care into the health system.<sup>lxi</sup> New perspectives have therefore suggested that policy diffusion occurs more between nations which are ‘similar,’ for instance in terms of socioeconomic indicators, rather than based only upon geographic proximity.<sup>lxv</sup> However, the extent to which palliative care has developed ‘similarly’ in ‘similar’ nations, is not known, a question which is returned to in Chapter Six.

In spite of the clear global diversity in policies and practices as well as the wide range of resources available to global organizations to influence social policies, Meyer is however dismissive of the power of global actors. He writes:

The structures of the world polity are mostly...not actors. They produce talk – scientific talk, legal talk, nonbinding legislation, normative talk, talk about social problems, suggestions, advice, consulting talk, and so on – not binding authoritative action [1999.p.127].<sup>lviii</sup>

This apparent generalisation does hold elements of truth. For instance, this analysis could serve as a critique of normative global agencies such as the WHO. As previously discussed, the WHO issues

standards, guidance and other recommendations they suggest that national governments and health practitioners should follow. For instance, the WHO Cancer Pain Ladder<sup>lxvi</sup>, evidence-based clinical guidelines on how pain should be treated or the recommendations within the WHA Resolution that palliative care should be part of the continuum of care. What they do not do, is fund the implementation of their policies nor wield binding influence over how nation-states should deliver healthcare.<sup>lxvii</sup>

However, the WHO exists alongside a complex array of actors in global health, many of which do have both the finance and the power to influence national health policies directly as has been demonstrated. Moreover, the direct transfer of policies of privatisation through conditional loans is too direct to be dismissed as a 'global force at work'.

The apparent failure of World Society Studies to account for the difference in policies and practices around the world, alongside their inappropriate dismissal of the ability of global actors to exert direct influence over national governments warrants attention. Additionally, it is not convincing to dismiss the influence of global-level policies on the policies and practices of nation-states. Both the MDGs and the SDGs did not simply 'emerge' but were formulated through processes of contestation and reconciliation of competing agendas. Moreover the vast amount of resources which are made available for meeting global goals following this prioritisation cannot be separated from the policies which led to their allocation. Thus, it is important to understand how policy is formulated at global level and how and why certain issues become prioritised at the expense of other valid claims. In this regard, a GSP understanding of policy development offers insight beyond the passive explanations offered by World Society Scholars to understand policy formulation within a "contested terrain of emerging global governance [Deacon, 2007. P.15]."<sup>ii</sup> We turn to this now.

### **Global Social Policy**

Global Social Policy (GSP) scholars refutes the extent of 'universalism' emanating to nations from the global level proposed by World Society Studies and dismiss the suggestion that global organizations are 'non-actors'. Instead, GSP scholars view the global level as a place where a wide range of actors contest appropriate social policy approaches in line with their own agendas.<sup>ii</sup> Moreover, they suggest that the role of the global governance system should be to further extend processes of global redistribution, global social regulation and global social rights.<sup>ii</sup>

By emphasising both the power and the agency with which global institutions are able to act, GSP scholars suggest that global organizations do not act purely in the interest of nation-states, but “develop their own ideas and pursue their own agendas [2004.p.2].”<sup>lxviii</sup> Additionally, GSP does not perceive the transfer of global norms, standards and institutions as occurring through passive, inevitable processes and instead, suggest that this occurs due to dynamic processes, emphasising the agency with which actors are able to act. On this basis, in order to make sense of how policies and practices are transferred both between nations and from the global level to nation-states, we turn to the theoretical framework of ‘policy transfer’.<sup>lxix</sup>

The policy transfer theory proposed by Dolowitz and Marsh<sup>lxx</sup> builds upon earlier work regarding policy *learning*, with both of these theories emerging from the premise that:

Every country has problems, and each think that its problems are unique...However, problems that are unique to one country...are abnormal...confronted with a common problem, policy makers in cities, regional governments and nations can learn from how their counterparts elsewhere responded [1991.p.3].<sup>lxxi</sup>

This position suggests that when faced with a common problem, it is rational to look at how others have responded to the same problem and to learn lessons – both positive and negative – from how the problem was addressed elsewhere. When these lessons directly, or indirectly, lead to the introduction of similar policies in alternative settings, Dolowitz and Marsh term this ‘policy transfer’. In their words:

Policy transfer, emulation and lesson drawing all refer to a process in which knowledge about policies, administrative arrangements, institutions etc. in one time and/or place is used in the development of policies, administrative arrangements and institutions in another time and/or place [1996.p.344].<sup>lxx</sup>

Policies and practices can therefore be transferred between all levels of the global governance architecture, with appropriate adaptations to context. For instance, between global organizations to nations (e.g. adoption of the WHA Resolution), from state to national level (e.g. India’s palliative care policy is based upon that of Kerala state<sup>lxxii</sup>) or between nations (e.g. Switzerland has now implemented its first community-led palliative care model based upon the Keralan model<sup>lxxiii</sup>). Such transfers are carried out across a spectrum, from voluntary transfer, to coercive transfers.<sup>lxx</sup>

Voluntary transfers occur when policymakers in one context identify a problem, or area of need and seek to identify how others in different contexts have dealt with a similar problem and then adopt similar policy – with appropriate adaptations for context. It has been suggested, however, that instances of *purely* voluntary transfer are rare and that this conceptualisation ignores issues of power within the policymaking context<sup>lxxiv</sup> and further raises concerns regarding the future adoption of opt-in policies such as the WHA Palliative Care Resolution. Additionally, whilst policymakers in settings where palliative care has not developed may look at other, similar countries, which have developed services, they would not be obliged to adopt similar or indeed any policies. Instead, any such implementation would rely upon policymakers both perceiving that lack of palliative is a problem and indeed having the political will to divert resources towards providing services.

At the other end of the spectrum coercive transfers take place either directly, for instance through conditional loans, or indirectly, due to factors such as interdependence and the formulation of international law which places obligations upon nations to respond with policies to abide by their terms.<sup>lxxv</sup> However, it is important to reiterate, that many ‘international laws’, whilst technically ‘binding’, such as the International Covenant on Human Rights are often not enforced.<sup>lxxvi</sup>

Conceptualising policy learning and policy transfer within this spectrum, hints that the potential for national governments to formulate policy purely voluntarily may be limited. Instead, a great deal of policy is formed within a system of formal and informal commitments, complex power relations and competing agendas at an increasingly important global level which is said to be accelerating processes of policy transfer.<sup>lxxvii</sup>

Within a context of competing discourses of competing health issues at global level, for instance a health systems approach to combatting illness Vs disease-specific interventions<sup>lxxviii</sup>, what then dictates how global policies are determined? Whilst recognising the influential role that IOs hold at global level, GSP also acknowledges the presence and influence of a much wider range of actors including, as previously acknowledged, knowledge networks International Non-Governmental Organizations (INGOs), and Transnational Corporations (TNCs) conflict and contest over policy at global level. A brief discussion of the active and potential influence that each of these groups may wield follows within a context of how certain issues become prioritised over others at global level and for the further development of palliative care.

## The Importance of Knowledge Networks

The transfer of knowledge, information and expertise is characterised in many different fashions. Diane Stone describes 'global knowledge networks' as "professional associations, academic research groups and scientific communities that organise around a special subject matter or issue [2002.p.2].<sup>lxxx</sup> Similarly, Peter Haas uses the term 'epistemic community' to characterise "a network of professionals with recognised expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area [1992.p.3]"<sup>lxxix</sup>. This discussion will adopt Jeremy Shiffman's understanding of a global health network as:

Cross-national webs of individuals and organizations linked by a common concern about a particular global health problem [2013].<sup>lxxx</sup>

Such networks are characterised by a broad range of institutions and actors, united in a common cause, which can include: development agencies, foundations, think tanks, universities, consultancy firms as well as individual experts and academics.<sup>lxxxi</sup> Shiffman argues that such networks are of interest as:

Many global health analysts present evidence that material factors such as mortality and morbidity burden and the availability of cost-effective interventions may not explain the variance in the levels of attention health issues receive [2009.p.608].<sup>lxxxii</sup>

This analysis calls to mind the discrepancy in global attention between infectious and non-communicable diseases at the global level, whereby communicable diseases have been prioritised – in spite of them representing a lower burden of global disease than Non-Communicable Diseases (NCDs). That is, that there must be another explanation for how issues become prioritised if policies are not solely formulated by targeting issues with the highest level of need. To understand the role of global networks within global policymaking processes of prioritisation, it is important to understand both how and why such networks emerge and how effective they can be in achieving their aims.<sup>lxxx</sup>

Networks may emerge in response to global legislation, for instance, in Argentina, it is suggested that the government's ratification of the Convention on the Rights of the Child opened the discursive space for rights-based advocates in the country to emerge.<sup>lxxxiii</sup> In this regard, there are perhaps

opportunities for palliative care activists in the Americas to further organise and make policy gains in response to the designation of palliative care for older people as a human right by the General Assembly of the Organization of American States in 2015.<sup>lxxxiv</sup> Here, however, the focus is upon how networks form in response to the apparent absence, or marginalisation, of issues at global level by actors who perceive them to be important areas of need.

Such networks form when actors, such as think tank experts, university academics and NGO researchers whom share similar values, causal assumptions and problem perceptions coalesce around issues perceived to be neglected.<sup>lxxxv</sup> Networks are formalised through regularised communication, the formulation of rules and resource divisions within the network. Over time, they may become institutionalised through the formation of advisory boards and through recognition by state and multilateral organizations in the formulation and implementation of policies. The formation of the European Association for Palliative Care (EAPC) Research Network serves as an example in terms of palliative care.<sup>lxxxv</sup>

It is suggested that the effectiveness of such networks is intrinsically linked to factors which led to their original formation as well as the features of the networks themselves, their policy environments and the characteristics of the issues they address.<sup>lxxxvi</sup> More specifically, Shiffman argues that robust networks are more likely to achieve their aims based upon the particular characteristics of the issues that they address. That is, in terms of severity of the problem in hand the tractability of the problem (how straightforward it may be to solve) and the nature of the affected population (such as children as a 'vulnerable group' who have not 'caused' the problem they suffer).

Viewed with this lens we gain further insight into the prioritisation of infectious diseases over NCDs. During epidemics, new populations may be infected across borders and infectious diseases may be visibly seen to be causing death high in numbers indiscriminately and are therefore easily perceived as 'severe' problems. Additionally, such problems may be perceived as 'solvable' due to the existence of vaccinations or known methods of disease control such as quarantining infected cases<sup>lxxxvii</sup>. By way of contrast, NCDs are often long term illnesses with a complex array of causes, and limited approaches to 'cures.' Moreover NCDs are predominantly found amongst older people, often considered a 'marginalised population' and whom *may* be considered to have caused their own illness through lifestyle choices.<sup>lxxxviii</sup>

This analysis presents a serious challenge for activists to present palliative care as a viable ‘solution’ to the global need of palliative care patients. Emergent palliative care knowledge networks, must therefore aim to ensure that the types of evidence for palliative care are able to clearly express why palliative care is needed, why it will help address the problem and how it can be implemented. Such evidence not only allows palliative care to be presented as a ‘solvable’ problem, but would also be in-keeping with the approach of funding agencies which use results-based approaches to financing.<sup>lxxxix</sup>

A further factor to consider in terms of considering why certain issues become prioritised relates to the extent of opposition to the introduction of any one policy. For instance, it may be argued that the prioritisation of infectious diseases is practical as there are fewer actors who may have competing interests when formulating policies to address them.<sup>xc</sup> To explain and expand upon this point, we turn to a discussion of the role and influence that Trans-national Corporations (TNCs) are able to exert on policies relating to global health.

### **Trans-National Corporations and global health**

Alongside neoliberal policies introduced by the international financial organizations, which promoted the privatisation of public services, globalisation has seen powerful business lobbies increase their power on the global stage as Trans-National Corporations (TNCs).<sup>ii</sup> The threats that TNCs pose to global public health are diverse. However, to narrow the discussion, here, the focus will be upon two different business interests that may be able to exert direct influence over policies aimed at improving public health, the tobacco and pharmaceutical industries.

In this regard, it is suggested that globalisation has increased both the power of corporations over governments.<sup>xc<sup>i</sup></sup> For instance, TNCs are able to shift capital and production and this threat of ‘capital flight’ encourages states to create favourable tax conditions for TNCs for fear of them moving elsewhere – at the expense of raising revenue for social welfare.<sup>xc<sup>ii</sup></sup> Indeed it has been argued further that the fundamental global business view of public provision of welfare services is that:

State provision is justified only if it contributes directly to economic growth or at least doesn’t undermine it, and is affordable only if it exists in an environment populated by profitable successful firms [Deacon. p.209. 2010].<sup>ii</sup>

This approach is consistent with that of the IFIs, but where TNCs impact upon global health more directly, is through trade agreements. Free trade agreement such as the Trans-Pacific Partnership Agreement in 2015 threaten to enable TNCs to limit the power of governments to implement policies aimed at improving the public health of their citizens as well limiting access to medical services and treatments through increased user fees.<sup>xciii</sup> Such trade agreements may therefore be seen as additional challenges for universal access to medicines adding to the potential for the pharmaceutical industry to make only expensive, patented palliative medicines available. What is more, such occurrences are in keeping with the rights of pharmaceutical companies to patent medicines for 20 year periods, enshrined in the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS).<sup>xciv</sup>

In this regard, it is important to emphasise that such trade agreements *oblige* nations to abide by them by law, once agreed, nations do not 'opt-in'. The interests of private companies may therefore become entrenched, at the apparent expense of public health. This is important for the palliative care community as it seeks a reduction in expensive treatments once they may be deemed to be 'futile'.<sup>xcv</sup> However, this existing approach to medicines is highly profitable for private companies who have a vested interest in the continuation of high usage of expensive treatments.

Yet, in spite of the apparent power and influence which transnational companies are able wield of global health policies, the extent to which palliative care community has engaged with this reality is not known. TNCs are therefore powerful actors at the global level, even if their presence appears to be more as limiters, rather than innovators in improving global health. It follows, that although TNCs do not explicitly set global health goals, they do have influence over what they are not. In this regard, it may be considered important to consider the potential role which they can play in either enhancing or limiting palliative care development.

However, if TNCs represent business interests, what role does civil society have to play in global health policymaking? To consider this question, here follows a short discussion regarding the final group of actors that will be focussed upon in this chapter: International Non-Governmental Organizations (INGOs).

## International Non-Governmental Organizations (INGOs)

The final group of actors for discussion here, are said to act as a buffer against the apparent democratic deficit in global policymaking circles: International Non-Governmental Organizations (INGOs)<sup>xcvi</sup>. These transnational civil society bodies represent a diverse range of interests, on behalf of which they lobby for greater global attention as well delivering interventions and conducting research. INGOs have few formal powers within global policymaking circles, however they are able to exert influence at global level through 'agenda setting'.<sup>xcvii</sup> INGOs such as Oxfam and Amnesty International are credited with a wide range of accomplishments, including putting climate change on the global agenda<sup>xcviii</sup> and forwarding the case for human rights.<sup>xcviii</sup>

INGOs are non-profit institutions and are able to operate either independently, or as recognised partners of International Organizations (IOs) such as the United Nations (UN). They are said to act as representatives of civil-society at global level and were described in 1995 by Kofi Anna, the former Secretary General of the UN as:

An essential part of the legitimacy without which no international activity can be meaningful [1995].<sup>xcix</sup>

Such organizations promoting palliative care are certainly emerging, both at the regional and global levels. For example, the European Association for Palliative Care (EAPC) is acknowledged by the Council of Europe<sup>c</sup> whilst the International Association of Hospice and Palliative Care (IAHPC) is in formal relations with the WHO.<sup>ci</sup> In this regard, palliative care INGOs may have a significant role to play in holding governments accountable to the apparent commitments they have made to providing palliative care through the signing of the 2014 WHA Palliative Care Resolution.

The legitimacy of INGOs themselves is, however, often contested and this characterisation of INGOs acting as 'guardians of public morals' is questioned, with critics pointing to a lack of democratic process within and between organizations.<sup>cii</sup> That is, that as non-elected bodies, they do not necessarily hold any legitimate claim to represent civil society and are not necessarily held accountable for their actions. Further, there is an inherent tension between the two roles that INGOs play, in terms of advocacy and service provision. As service providers, INGOs actively enter the governance system of global development, instead of acting as critique of this system. INGOs may win contracts from IOs to deliver services at national level. However by doing so, their

imperatives towards agitating for social change and social justice may be compromised as they grapple with the tensions of securing lucrative organizational contracts and the associated limitations that such grants place up on the ability of INGOs to act independently.<sup>ciii</sup>

These may be considered significant issues which palliative care INGOs must grapple with. In terms of service provision however, INGOs such as the EAPC, provide technical assistance, but do not themselves implement services, which may reduce any potential conflict of interest. A more serious challenge therefore relates to the representativeness of palliative care INGOs of the wishes of civil society. In this regard, it was identified in Chapter Two, that global need for palliative care is often presented technocratically, with experts *saying* that there is a need for palliative care. It is therefore essential, that the research community generates evidence that patients want palliative care and that it is acceptable to them. Whilst there are rational arguments, that pain medication is an appropriate response to pain, as global policymaking becomes ever more evidence-based<sup>civ</sup>, it is important to be able to back claims that there is a need for palliative care with robust evidence. However, the extent to which the international palliative care community is generating such evidence is unknown, a question which is addressed in the Chapter Five.

The existence of a robust evidence base would allow INGOs to use differing and nuanced ‘frames’ with which palliative care could be presented to appeal to different actors. However, though palliative care INGOs hold the potential to influence global policymakers they sit alongside a wide range of other health policy claims. How then are certain health lobbies able to influence policymakers over and above other valid claims? In this regard, the final section of this chapter looks beyond the field of palliative care, in order to examine how other health lobbies have successfully attracted policy interest, to determine what the field of palliative care may be able to learn from other fields in order to accelerate development.

### **Addressing global social problems through advocacy**

As demonstrated in this chapter, global health policies cannot be characterised simply as responses to areas of global need or as the provision of global public goods. Policy prioritisation has been described more in terms of how different actors exercise their relative power and resources to determine policy priorities.

In this regard, advocacy can play a key role in determining which health issues become considered 'global issues' or 'global problems'. Throughout this thesis, advocacy is understood as:

A range of activities aimed at persuading decision makers to design, adopt, and change policies and practices to secure direct and lasting benefits for the people we work with [Bryer and Magrath.1999.p.170]

It is suggested that the potential for advocacy efforts to achieve change centres around two key characteristics of campaigns; credibility and salience.<sup>lxxxii</sup> By credibility is meant, how 'honestly' social problems are represented whilst salience refers to the relevance of issues to key stakeholders including public opinion. This links to the key tenets of a successful advocacy campaign as suggested by Ann Pettifor, the architect of the Jubilee 2000 campaign, which saw approximately \$100 billion of debt written off for developing nations.<sup>cv</sup>

Pettifor argues that the cornerstone of a successful advocacy campaign rests on several key factors. Firstly, understanding the context within which the campaign will operate in terms of the political, economic and social terrain is key, issues which this chapter has considered and which are returned to in Chapter 6. Within this, activists must consider who potential allies may be as well as actors who may oppose the issue being promoted as identified above in terms of palliative care and TNCs. Secondly, Pettifor emphasises the need for: 1) a clear articulation of the problem in hand; 2) clearly defined goals and the need for clear 'asks' of an advocacy campaign; 3) pre-determined rebuttals of opposing arguments; and 4) use of appropriate 'frames' of the issue to the differing key actors that the campaign aims to influence.<sup>cv</sup> Yet, in spite of this complexity, Shiffman argues that:

Almost all [health advocacy communities] take the same two rhetorical steps: first making a "problem" claim surrounding *severity* and *neglect* of their issue, and then a "solution" claim surrounding the problem's *tractability* and the benefits that would accrue from addressing it [p609.2009].<sup>lxxxii</sup>

This analysis raises significant challenges for palliative care advocates. As was identified in Chapter Two, the global need for palliative care is not well understood by global policymakers. Moreover, palliative care patients are likely to have complex symptom burdens which require multi-faceted solutions and indeed palliative care is considered a 'complex intervention'.<sup>cvi</sup> The many elements of palliative care including pain management, emotional support etc. make their presentation as a

tractable solution to patient suffering challenging. Moreover, the varied ways in which palliative care can be delivered again raises questions regarding the ‘universality’ of different elements of palliative care and would appear to limit the potential to clearly define a ‘problem’ and ‘solution’.

Furthermore, the broad similarity between all advocacy campaigns which sit alongside palliative care, through the presentation of ideational issues, raises questions regarding how certain issues attract the attention of policymakers at the expense of others?

Amidst competing claims, social constructionists argue that issues are not prioritised based on their actual importance, but based upon how important the issue is *portrayed*.<sup>cvi</sup> Within this context, the importance of INGOs is increased due to the necessity for strong institutions to underpin successful advocacy campaigns. Understanding institutions as “rules, norms, and strategies adopted by individuals operating within or across organizations [p.37.2007]”<sup>cvi</sup>, INGOs are an organizational embodiment of advocacy. The power of such organizations lies in their ability not only to mobilise people and resources around a particular issue, but to maintain and negotiate how issues are ‘framed’ in response to changing contexts and challenges. For instance, Advocacy International is currently working upon a campaign which aims to re-frame maternal mortality, from an emphasis upon mortality, to a focus on effective solutions. The MamaYe campaign emphasises survival rather than mortality and is engaging local communities with stories of successful treatment and a campaign to ‘give blood to save a Mama’.<sup>cix</sup> It may be suggested, that such campaigns helped ensure that maternal mortality, was not superseded by new health ‘*trends*’ and was included as a specific indicator of the SDGs.

However, whilst re-conceptualising problems is one way of attracting attention, GSP scholars focus upon the relative power of established frames in terms of their likelihood of influencing policymakers. Accepting that there may be alternatives, Labonte and Gagnon focus upon six policy frames and rank their potential to influence health policy: 1) national security; 2) international development; 3) global public goods; 4) trade; 5) human rights; and 4) ethical/moral reasoning.<sup>cx</sup> The authors argue that each frame holds the potential to influence policymakers to differing degrees, with health issues presented as ‘national security’ threats the most likely to attract attention. The ‘national security argument’ was one which attracted great attention for HIV/AIDs and the same argument has been used to mobilise resources more recently, for the Ebola outbreak in West Africa.<sup>cx</sup> Security is followed by development and provision of global public goods as the most pervasive frames, significantly, when these frames are presented as economic issues or as means, or limiters, to economic growth.

Frames promoting trade as a means to improve health by way of market integration and economic growth are ranked fourth in this categorisation, whilst normative arguments for health as a human rights issue or moral/ethical problem rank as the frames least likely to influence national-level policymakers. It is suggested, that for ethical or moralistic frames to achieve influence, there must be some legal underpinning to claims of advocates, for instance through international conventions. However, the authors pessimistically conclude:

Neither moral nor legal argument, in the absence of enforcement mechanisms, is necessarily compelling as an economic or political rationale [2010].<sup>cx</sup>

Yet, apparently contrarily, they also argue:

Economically, both the global public goods and development frames have some health utility in foreign policy debates, but only if they are located beneath a penumbra of ethical reasoning and legal obligation [2010].<sup>cx</sup>

This analysis provides lessons for the palliative care community and supports the idea that advocates must present their issue within a variety of frames to consider what may resonate with a diverse range of actors at all levels of governance. Palliative care has, however, never been theorised in such terms and there appears to be a continuing reliance upon presenting global need for palliative care statistically as well as human rights arguments for its implementation. Moreover, it is not known, the extent to which researchers are producing evidence which is internationally relevant to equip knowledge networks and INGOs with evidence-based arguments upon which to frame palliative care need as a problem and provision as the solution.

## **Discussion**

The application of theoretical understandings of global policymaking processes to understand palliative care as a global health issue, raises significant opportunities and challenges for the further development of the field. In terms of challenges, it has been shown that global policies are not formulated solely in response to level of need. Additionally, the provision of palliative care does not appear to be an issue which can be presented as a 'public good' as it is a problem which is experienced by patients and families and does not present a wider threat to communities or other

nations. Moreover, it appears that the global level organizations which are engaging with palliative care issues, such as the WHO, lack the power to implement their own policies within nations directly.

However, other global-level actors including funding agencies, knowledge networks, transnational companies and INGOs have emerged as potential powerful actors for change. Yet, whilst funding agencies have the power and resources in order to directly implement palliative care policies and practices within nations it does not appear that the palliative care is yet producing nuanced, evidence-based arguments in order to engage with them. Moreover, creative 'frames' for palliative care are unlikely to gain traction without firm evidence, a notion backed by the suggestion that moral and ethical arguments, are the least likely to influence policymakers. This is an uncomfortable truth, however it is one which the palliative care community must engage with.

That funding agencies operate 'results-based financing' and that advocacy efforts gain the greatest traction when defining both problems and solutions clearly, represents key challenges to the field of palliative care. Moreover, whilst there is evidence from countries such as the United Kingdom, of the effectiveness of palliative care it has not been established whether such evidence has broader implications.<sup>cxii</sup> Additionally, whilst there are countries where *no* palliative care services exist to be evaluated, it is important to establish whether palliative care researchers are producing evidence which has international relevance. Dynamic forces have been identified which have shown that practices and policies have developed based upon geographical proximity, however, it is not known the extent to which such processes have relevance for nations in other geographic locations.

To address this gap, Chapter Five presents a Systematic Mapping of Review of International Palliative Care Research in order to establish whether palliative care researchers are overcoming barriers to high quality research identified in Chapter Two, to produce the types and strength of evidence with which advocates are able to creatively 'frame' palliative care to global policymakers. Before doing so however, the following chapter presents the overall methodological strategy of the thesis. A multiple-methods approach is justified, explaining how a methodologically iterative approach allowed original research questions to emerge during processes of ongoing reflection and revelation.

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## Chapter Four

### Methodology

#### Introduction

In Chapter Two a brief history of international palliative care was given to show that existing narratives of development have been conceptualised only simplistically and without sophisticated consideration of theoretical understandings of policy spread and development. As a potential remedy, the previous chapter offered a Global Social Policy (GSP) perspective as a critical lens through which to consider how palliative care may be able to achieve policy prioritisation. It was argued, that in order for palliative care development to be accelerated, that new approaches were needed including new ways of ‘framing’ palliative care based upon evidence-based arguments.

The intention of this short chapter is to set out the overall methodological approach of this study in order to answer the research question:

*Can the global development of palliative care be furthered through increased understanding of global policymaking processes and the presentation of palliative care as an international development issue?*

As will be explained below, in order to answer this question, the research was divided into three distinct phases, each of which had distinct sub-research questions and required the use of distinct methods. Overall, a largely qualitative approach was adopted, but multiple methods were employed in order to answer several additional more focussed sub-research questions which were generated iteratively during the course of the research. On this basis, this chapter presents a brief overview of the methods employed by the study, with more detail and discussion of their utility presented in subsequent chapters. It proceeds to consider the broad research paradigm adopted in order to justify both the iterative study design as well as the employment of a multiple methods research strategy. The chapter concludes with consideration of ethical risks faced by the project, which, due to the lack of any medical intervention, vulnerable populations and full consideration of ethical issues throughout the project from design to delivery, may be considered low.

## Overview of methods

Three different research methods were adopted during the project, to answer the overarching research question as well as additional questions which emerged during the project in line with the inductive approach used throughout the study.<sup>i</sup> On this basis, the project was conducted in three distinct phases:

1. A systematic mapping review of international palliative care research
2. Quantitative analysis using correlations between structural indicators of country development and level of palliative care development
3. Semi-structured, qualitative interviews of key experts within the field of international palliative care

Due to this diversity, the specific methods including the sub-research questions, study design, data collection, data analysis etc. are presented separately within subsequent, free-standing, but linked chapters for each element of the study. The focus in this chapter is therefore to consider the overall research paradigm adopted by the study as well as to justify the use of multiple methods as a rational way of answering different sub-research questions.<sup>ii</sup> As each method was utilised to answer specific, but linked questions, no formal process of triangulation was used.<sup>xxiv</sup> However, in various ways, findings from each element of the study interact to either support or challenge each other. Therefore, ways in which the findings from each part of the study coalesce in order to answer the overall research question are considered.

This multiple methods study was guided by an iterative approach to research design, whereby the methods employed were guided by emergent areas and questions of interest.<sup>iii</sup> This approach reflects the wide ranging scope of the study and was deemed appropriate to both answer specific questions (systematic review, correlations) as well as to answer broad questions (elite interviewing) regarding international palliative care advocacy, questions which were developed based upon emergent findings. Therefore, the multiple-methods approach was adopted not to duplicate and validate findings<sup>iv</sup> (although instances where this occurs are noted through the study), but to produce complementary findings and increase understanding of the complex field of international palliative care development. On this basis, theory development was driven through inductive process, which allowed theory to emerge from the data, rather than through examination of existing theories through hypothesis testing.<sup>v</sup>

Although there is a long tradition of the employment of multiple methods in order to answer complex questions, their use is not universally accepted.<sup>vi</sup> It is therefore appropriate to provide justification for the methodological approach employed by this study and to consider the overall robustness of the approach and understand just what it is appropriate to infer from findings arising from the use of multiple methods. The following section therefore reviews the research paradigm used by the study as well as some of the debates regarding the utility of the methodological approach adopted.

### **Research paradigm and approach**

All research is undertaken within a selected research paradigm, which serves to dictate the types of questions which may be considered 'answerable' and consequently the methods which can be used. 'Research paradigm' is a broad term, which is said to encompass specific elements including: ontology and epistemology.<sup>vii</sup> Ontology is a term which questions the nature of reality, in terms of whether researchers study objective reality as something which is pre-existing, waiting to be discovered, or if it is something which is constructed through processes of interaction.<sup>viii</sup> Epistemology relates to theoretical understanding of the nature of knowledge and investigates the origin, nature and limits of human knowledge.<sup>ix</sup>

Consequently, different epistemological positions allow researchers to answer different questions, based upon understandings of reality and therefore different methods are adopted in order to answer differing questions. In practice, different understandings of epistemology, lead to differing claims from researchers regarding the validity of knowledge which emerges from research findings. A key distinction between two epistemological positions may be drawn by understanding two schools of thought on polarised sides of the divide: positivism and interpretivism.

Positivists believe that reality exists independently from researchers and therefore, that 'knowledge' is something which is pre-existing which can be proven to be certain through the production of replicable results. For instance, in medical research, 'knowledge' may be generated through the use of experimental studies and quantitative research methods, to answer questions such as: is drug X effective in curing disease Y?<sup>v</sup> On the other side of the debate, interpretivists perceive of knowledge as something which is intentionally constituted through lived experience. Interpretivists do not seek to prove social phenomena, but aim to make defensible knowledge claims, through the use of qualitative research methods.<sup>x</sup>

The research questions formulated within this study do not allow definitive answers to be generated using a positivist approach. Interpretive research is often criticised by positivists due to the non-replicability of research findings.<sup>x</sup> This study, however, rejects such criticism and operates mainly from an interpretivist standpoint that seeks to understand social phenomena emerging from data collected during qualitative interviews.<sup>xi</sup> It follows that semi-structured interviews were conducted, in order to ascribe meaning to participant responses and increase understanding, rather than to generate objective ‘facts’.<sup>vi</sup>

However, through examination of statistical indicators of country development as well as the use of level of palliative care development as an ordinal outcome measure<sup>xii</sup>, the study also draws upon an epistemological position which combines principles of both interpretivism and positivism – rejecting the idea that the two positions are incompatible. In doing so, it accepts the possibility that more than one truth may exist regarding phenomena. This position is informed by the argument that:

Interpretive analysis can provide crucial information to inform positivist causal theories that might otherwise have been missed [2013.p.161]<sup>xiii</sup>

This situation can be seen most clearly, through informal discussion in Chapter Six of palliative care development, which draws upon statistical indicators of the structural contexts within which palliative care services have (or have not) developed. Emergent findings were then critiqued and corroborated using the views of key experts in international palliative care research regarding factors which have driven development.

However, it is important to acknowledge, that the study draws upon a positivist approach through the use of correlations between structural indicators with level of palliative care development, for their explanatory value only. That is, correlations were used to describe the contexts in which palliative care has developed, not to develop any causal assumptions. On this basis, regression analysis was not conducted as the chapter does not seek to suggest that any one indicator causally effects level of palliative care development, only that they are associated.<sup>xiv</sup>

It is common in *mixed* method studies, to employ triangulation, in order to cross-check findings and answer a single research question.<sup>xxiv</sup> This study, however, does not do so as different methods were used iteratively in order to answer emerging questions from data. That is that diverse methods were employed to answer different questions, rather than to validate a single answer to a single question.

It follows, that the study is presented as using 'multiple methods' rather than 'mixed methods'. A mixed-methods approach often asks confirmatory as well as explanatory questions concurrently in order to corroborate results obtained using qualitative and quantitative methods to answer the same question.<sup>xv</sup> 'Multiple methods' is a more appropriate conceptualisation of this study, however, as it describes the use of distinct research methods within an overall project, which incorporates more than one study. Additionally, each different study design exists in relative isolation, whilst also contributing towards answering the overall research question.<sup>xvi</sup>

The study therefore operates mainly from an interpretivist standpoint and seeks to understand social phenomena emerging from data collected during qualitative interviews.<sup>xvii</sup> Such methods are relatively new in health care research, which more commonly aims to produce replicable results for instance in terms of proving whether a certain drug therapy is effective.<sup>vi</sup> In this regard, the study draws upon purposive and snowball sampling of key experts and imparts inductive reasoning in order to increase the validity of broader findings. Nevertheless, it must be acknowledged, that using such an approach means that findings cannot be disaggregated from the role of the researcher in producing them.<sup>xviii</sup> Additionally, generation of data through interviews relies on interaction between a researcher and study participants and therefore the social world which is present to be understood, is bounded within the confines of the knowledge and experiences of both the researcher and the research subjects.<sup>xix</sup>

### **Risk of researcher bias**

One methodological risk which ran throughout the study was that of 'researcher bias'. That is, due to the active presence of the researcher in the research process, there was a risk that results may be influenced due to the active process of their generation.<sup>xx</sup> This active role played by the researcher holds the potential for individual bias to be introduced into a project at all stages as the following quote explains:

A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions [2001. P.485].<sup>xxi</sup>

Within this study, the role of the researcher became ever more active during processes such as coding, through which meaning was ascribed to study participants' words as well as during analysis, where decisions were taken regarding which elements of participants' responses were important to the research question. Indeed, due to the large amount of data generated through interviews, it was incumbent upon the researcher to bring coherence and structure to the data.<sup>xxii</sup> This circumstance arose also, when conducting the systematic mapping review [Chapter Five], where judgement calls were necessary to determine whether papers met the inclusion criteria as well as to which thematic category they should be assigned. Thus, without appropriate safeguarding, the risk of researcher bias was present throughout the study.

In order to meet this methodological challenge, reflexivity was exercised by the author at all stages of the project. Reflexivity may be defined as "an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process [Wood.2015]".<sup>xxiii</sup> In this regard, the internal reliability of processes such as coding was tested through the involvement of a second/third researcher in such processes.<sup>xxiv</sup> That is, that some transcripts were double coded and decisions regarding inclusion/exclusion of research papers within the systematic review were reached by two researchers independently making such decisions, then cross-checking and with final decisions reached through consensus. However, in instances where there was divergence of opinion, final decisions were made by the author. More detail regarding such efforts is provided within distinct methods sections of subsequent chapters, however, such issues are important to acknowledge here, to underline that a robust methodological approach was adopted throughout the study, in order to increase the overall validity of research findings.

### **Theoretical underpinning and ethical approach**

In terms of theoretical approach, this thesis draws upon Global Social Policy (GSP) explanations of global policymaking processes. However, it is important to acknowledge, that whilst theoretical literature is drawn upon to increase the validity of findings, that this study does not seek to empirically test any GSP assumptions. Instead, theoretical literature is drawn upon to increase understanding of global palliative care development, based upon pre-existing theoretical understanding of processes of policymaking and prioritisation. Accordingly, where appropriate, findings which support GSP perspectives are noted. Additionally, where phenomena appear to occur for which a GSP theoretical perspective does not increase understanding, GSP is critiqued appropriately. On this basis, the study should appeal to both palliative care and GSP audiences.

Finally, although this project may be considered 'low risk' in terms of ethical issues arising, this study began from an understanding that in qualitative research, the validity of research findings is reduced if research has not been conducted to high ethical standards.<sup>xxv</sup> In line with the overall methodological structure of the study, any relevant ethical considerations specific to each chapter are considered alongside more detailed discussion of the research methods for each. However, here it is appropriate to note, that in terms of research procedure, the study was conducted in line with principles of Good Clinical Practice and the Declaration of Helsinki.<sup>xxvi</sup> The study received full ethical approval from the University of Sheffield, School of Health and Related Research (ScHARR) Research Ethics Board on the 27<sup>th</sup> April 2015 [Appendix 1].

## **Conclusions**

This chapter has described and reflected upon the overall methodological strategy of the study. The use of a multiple methods approach has been justified as a rational method of answering different questions. It has also been shown why a largely qualitative, interpretive approach was selected in order to answer the overarching research question of the study, for which no objective 'correct' answer is possible. Instead, through rigorous research process and appropriate safeguarding, the findings in response to separate questions will be synthesised in order to provide a methodologically justifiable knowledge claim.

In Chapter Three, key insights from the field of GSP were presented in terms of how global health policies are formulated and why certain issues receive policy prioritisation over and above other worthy claims. It was argued that palliative care development may be accelerated through the presentation of evidence-based 'frames' to global policymakers who have the power and resources to fund service development. However, the extent to which researchers are equipping advocates with evidence which is internationally relevant is not known. On this basis, the next chapter presents a Systematic Mapping Review of International Palliative Care Research to identify whether researchers are providing evidence to advocates which is likely to influence global policymakers.

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## Chapter Five

### A Systematic Mapping Review of International Palliative Care Research

#### Introduction

As identified in Chapter Two, globally speaking, the need for palliative care continues to greatly outstrip supply. In spite of this, recognition from global level actors has been limited, with palliative care receiving attention mainly from normative and civil-society organizations and little or no engagement from funding agencies. This circumstance is of concern to the global development of palliative care, as normative institutions do not hold the power to implement policies and projects services and instead rely on the production of guidance and their primary roles are to set standards and provide leadership.<sup>i</sup> In this regard, it has been argued that engagement is needed from a wider range of global actors with the resources in order to fund palliative care development within low-income contexts. However, in order to engage with powerful global health care actors it is necessary to make evidence-based claims to attract the attention of global policymakers.<sup>xii</sup>

Drawing upon Global Social Policy theory (GSP), it has been identified in Chapter Three how policies and practices can be transferable between nations. Additionally, it has been shown that policy claims gain greater traction, when social problems are presented as 'solvable' and the message is delivered by a wide range of actors, through international research networks and International Non-Governmental Organizations (INGOs). Furthermore, it is known that in order for health issues to attract the attention of policymakers, an evidence-base is required.<sup>ii</sup> 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.

However, the extent to which researchers are facilitating such processes by producing research which has international relevance, is unknown. It is this from context that this chapter emerged.

## Rationale for the review

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.<sup>iii</sup> 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.<sup>iv</sup> 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 in spite of 'global ageing' emerging as a key area for international development.<sup>v</sup>

The primary aim of palliative interventions is to improve the quality of life of patients facing life-limiting illnesses and their families.<sup>vi</sup> However, it is also suggested that increased access to palliative services through a public health approach holds the potential for broader benefits including reduced overall health expenditure through reduced usage of primary and critical care<sup>xi</sup> and reduced out-of-pocket expenditure for households.<sup>vii</sup> Additionally, national studies have demonstrated that palliative care can reduce unnecessary and expensive hospital admissions.<sup>viii</sup>

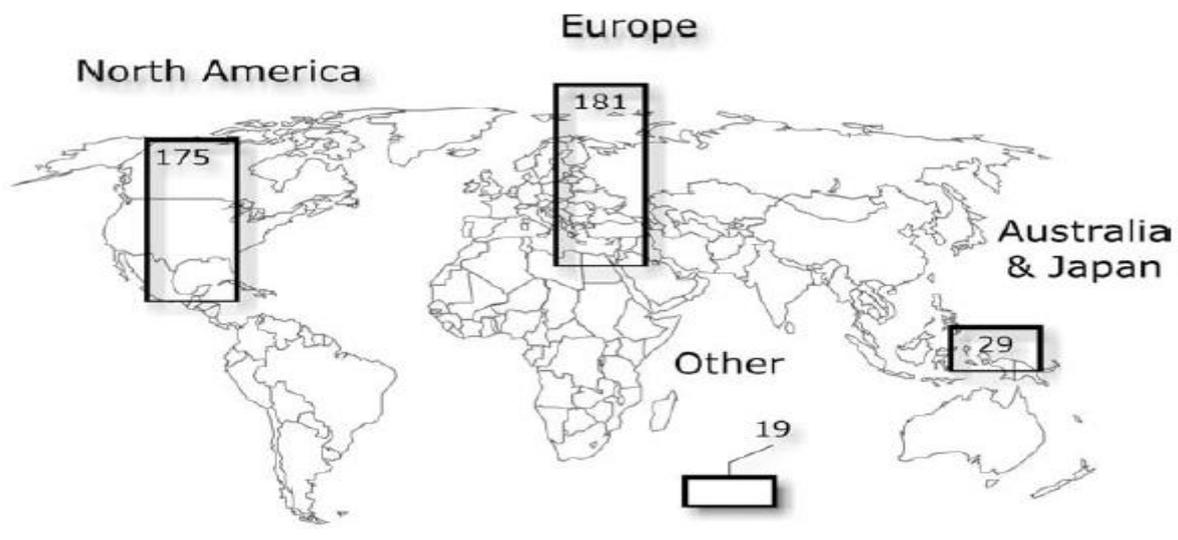
Conceptualising palliative care in economic terms as well as an urgent health need, would allow its consideration as an international development issue which aims to increase levels of both human and economic development.<sup>ix</sup> Moreover, as referred to in Chapter Three, many of the key global health actors, such as the World Bank, prioritise development models through economic mechanisms, which suggests that evidence supporting economic arguments for palliative care may be an effective way of engaging with new financiers.

However, in spite of many studies demonstrating a link between illness, death and household poverty in both low<sup>x</sup>, and high-income settings<sup>vi</sup> little global attention has been given to how such 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,<sup>xi</sup> attention to the financial aspects of illness and bereavement is warranted. Additionally, presenting palliative care in this manner may be considered an innovative 'frame' with which to engage policymakers as part of broader development efforts towards poverty reduction.<sup>ix</sup>

It is known that in order for health issues to attract the attention of policymakers, an evidence-base is required.<sup>xii</sup> In this regard, palliative care as a research field has grown alongside global development of services with output increasing yearly.<sup>xiii</sup> In 2002, a systematic review of empirical palliative care research was conducted which located around 400 papers – around 90% of which had been conducted post-1990. By 2011, a paper entitled ‘World-wide literature survey on geriatric palliative medicine’, identified 404 papers - 323 of them primary research studies - within only the five year period between 2007-2011.<sup>xiv</sup> Although the two studies did not compare like-for-like outcomes, this nevertheless indicates an exponential rise in palliative care research activity.

However, there are ongoing concerns regarding the evidence-base that palliative care researchers are providing to policymakers.<sup>xv</sup> 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 researchers lack the resources to inform the delivery of appropriate care.<sup>xvi</sup> In this regard, Figure 4 presents the results of a review of geriatric palliative care and shows that poorer regions are contributing little to the evidence base.

**Figure 4. Global Geriatric Research Publications, 2006-2011 by Continent**



Source: Curiale, V. 2011.<sup>xiv</sup>

Additionally, there are various barriers to the production of high-quality research, such as, ethical issues associated with conducting research on vulnerable populations.<sup>xv</sup>

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.<sup>xvii</sup> 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.<sup>xviii</sup> 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.<sup>xix</sup> However, with an urgent need for research collaboration between low and high-resource countries<sup>xx</sup>, 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. 'International research' was defined as involving two or more countries due to the potential of comparative research to increase common understanding.<sup>xxi</sup> 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, the extent to which attention is focussed upon low-income countries where little palliative care research is known to be conducted by national researchers is considered. Finally, this chapter analysis asks 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.

This systematic mapping review therefore aimed to answer the following specific questions:

1. What is the typology of academic literature focussing on palliative care in a global context?
2. What are the research strengths of the field and where is evidence lacking?
3. Where and when has research been produced?
4. Which countries and world regions is research focussing upon?
5. Is the research field growing?

To answer these questions, a study selection strategy was developed in order to identify relevant information and is presented below.

## **Methods**

A systematic mapping review is an established literature review method that is employed in order to map out and categorize existing literature from which to commission primary research by identifying gaps in the research literature'.<sup>xxii</sup> 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.<sup>xxiii</sup>

### **Search strategy for Identification of Studies**

In line with the aim of the review to produce a picture of the full academic field of global palliative care research, the search strategy was designed to be as sensitive and systematic as possible.<sup>xxiv</sup> By doing so, it was recognised a consequence of this was that many of the returned outputs would not be relevant to the study. However, a more specific search strategy was likely to have missed many outputs relevant to the review and thus an inclusive approach was taken.

To ensure that an appropriate search strategy was developed, a scoping exercise of keyword terms was undertaken. Search terms were developed through consultation with an expert in palliative care research (CG) and an expert in global social policy research (AK). Terms were initially developed iteratively based upon existing knowledge of the field which were then checked for synonyms using a thesaurus.

There was some disagreement as to whether certain terms should be included – for example, 'universal' when searched with 'palliative'. Here, the interdisciplinary team worked well. CG, as the palliative care lead, argued that 'universal palliative care tends to be used a synonym for generalist palliative care rather than international palliative care'. Conversely, AK stated that 'the term is used in the global social policy literature, particularly diffusion/world society theory'. After discussion, it was decided that the term should be included, as searching for 'universal AND palliative', would produce outputs relevant to universal health coverage and the exclusion criteria would remove the 'generalist palliative care' literature – unless it had an international perspective.

After the consultation process, search terms were decided upon for a scoping exercise and are presented in Table 3. The scoping exercise was conducted by searching ‘topic’ with all of the key words and search terms in Web of Knowledge with the root term, ‘global’. In general, the exercise produced manageable results, for example, what was anticipated to be one of the major searches, “global AND palliative” returned 708 outputs. Problems did emerge, however, from two of the suggested key words – ‘death’ and ‘dying’. When searched with ‘global’, the two terms produced ‘approximately’ 29,775 and 10,813 outputs respectively. This figure it was agreed was, practically, too high to apply the inclusion/exclusion to.

**Table 3: Provisional search strategy for scoping exercise**

<b>Root terms (having searched and included synonyms)</b>	<b>Key words to be searched with Root terms (having searched and included synonyms)</b>	<b>Search terms (to be searched with and without hyphenation as appropriate)</b>
Global	Palliative	"Opioid availability"
International	Palliation	"supportive care"
Europe	Palliat	"Terminal illness"
Africa	Hospice	"Terminally ill"
Asian	Death	"Terminal disease"
North America	Dying	"end-of-life-care"
South America	Bereavement	"Terminal care"
Transnational		
World		
Worldwide		
Developing World		
Universal		
Supranational		
Multinational		

A further scoping exercise was undertaken. The inclusion/exclusion criteria were applied to the first 100 returned results for the searches “global AND dying” and “global AND death” to assess how many of the returned outputs would be relevant to the study and not picked up by any of the other search terms. The search for ‘global AND death’ produced only one output which would be included in the study, but as the output would have been found by ‘global AND palliative’, it was decided that ‘death’ could be removed from the search strategy.

The search for ‘global AND dying’ produced four outputs which would be included in the study – only three of which would have been located by the existing search strategy. As a result, the term ‘end-

of-life-care' was refined to 'end-of-life' to ensure that the output entitled 'Researching the end-of-life in old age: cultural, ethical and methodological issues'<sup>xxv</sup> would have been identified, although this specific paper was not eventually included.

Although the amended search strategy would have found all four included outputs from this search, it was decided that further refinement of the search strategy was necessary, as excluding 'global AND dying' when 4/100 outputs were relevant was deemed unacceptable. As a result, it was deemed that the terms 'global AND dying AND care' and global AND "care of the dying" should be investigated. The returned results were as follows:

global AND dying AND care = 637 returned outputs.

global AND "care of the dying" = 3 returned outputs.

With the higher results returned by 'global AND dying AND care', the inclusion/exclusion criteria were again applied to the first 100 returned outputs. Three papers were identified in this manner, but all had been found by alternative searches and it was agreed that the term should not be added as it had yielded nothing new from a high amount of returned outputs (637). It was decided that 'global AND "care of the dying"' should be added to the search strategy as it had yielded relevant outputs (3) from low returned search results (also 3). Other minor changes made after the scoping review were that 'Asian' was changed to 'Asia', and 'Developing Countries' was also added. In addition, terms where the 'root' of a word would find the longer term (for example, palliat\* and palliative/palliation) the longer terms were also removed to simplify the search process.

The scoping review was performed and the results verified and discussed with a palliative care expert (CG). This scoping exercise led to the following changes being made to the search strategy.

**Removed;**

Death, dying, 'end- of-life-care', Asian, worldwide, 'developing world', palliative, palliation

**Added**

'care of the dying', 'end-of-life', asia

Following this scoping exercise of keyword search terms, the search strategy using MeSH headings and keywords was formulated [Table 4] and agreed with an Information Specialist, experts in the

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

**Table 4: Summary of search strategy for systematic review**

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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

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

---

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. In order to meet the aims of the review, a list of inclusion/exclusion criteria was devised [Table 5].

**Table 5: 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 where national research explicitly expresses international relevance 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

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**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

---

**Applying the Inclusion/Exclusion Criteria**

Once the searches have been performed, the inclusion/exclusion criteria were applied to the returned results. A total of 11613 articles were initially reviewed using title/abstract, of which 11123 articles did not meet the inclusion criteria [Figure 5]. Full text articles were then retrieved for the remaining 490 papers and the inclusion/exclusion were applied by JC. Most of these papers were retrievable through the University Library or were available online through open access. Additional papers were retrieved by attending the British Library sites at both Boston Spa and London. Following this, a second independent screening of all included titles/abstracts was undertaken by CG and consensus agreed by discussion in cases of disagreement. Where there was any confusion regarding the relevance of the output, the full paper was consulted once more and the final decision

made by the author. During this process, regular discussions were held wherever decisions had to be made regarding the eligibility of studies. Each meeting was minuted and during the discussions, several broad decisions were reached regarding the following issues.

### **Papers relating to euthanasia/assisted dying**

It was decided that such papers would be excluded, as although there are conflicting viewpoints, there are several statements from palliative care organizations which specifically state that assisted dying and euthanasia are not part of palliative care.<sup>xxvi</sup> The exception to this rule was that any relevant papers commenting on the subject from a palliative care standpoint would be included.

### **Non-Empirical papers**

Many published articles (n=306) relevant to palliative care in international context were identified by the search strategy which did not meet the inclusion criteria as they did not report using research methods e.g. discussion pieces, editorials, letters etc. Typically, such articles offered evidence-backed arguments, but did not contribute new material to the evidence-base. Articles excluded from the review within this category were retained to inform analysis of both the review and the broader project.

### **What is 'international'?**

The inclusion criteria provide a clear explanation of how 'international' research was defined [Table 5]. However, an issue which arose whilst applying the Inclusion/Exclusion criteria, was how to deal with outputs relating to settings with differing understandings of sovereignty. For instance, England, Scotland, Wales and Northern Ireland may be understood as individual nations, or as the United Kingdom (UK). Likewise, Hong Kong may be treated as a sovereign nation or as part of China. A consistent approach was used for understanding nations by adopting the UN country classification system. On this basis, one article which compared hospice practices in England and Wales<sup>xxvii</sup>, the UK was treated as a national study and excluded, although it is acknowledged that there has been devolvement of healthcare in this circumstance from the UK government.<sup>xxviii</sup>

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.

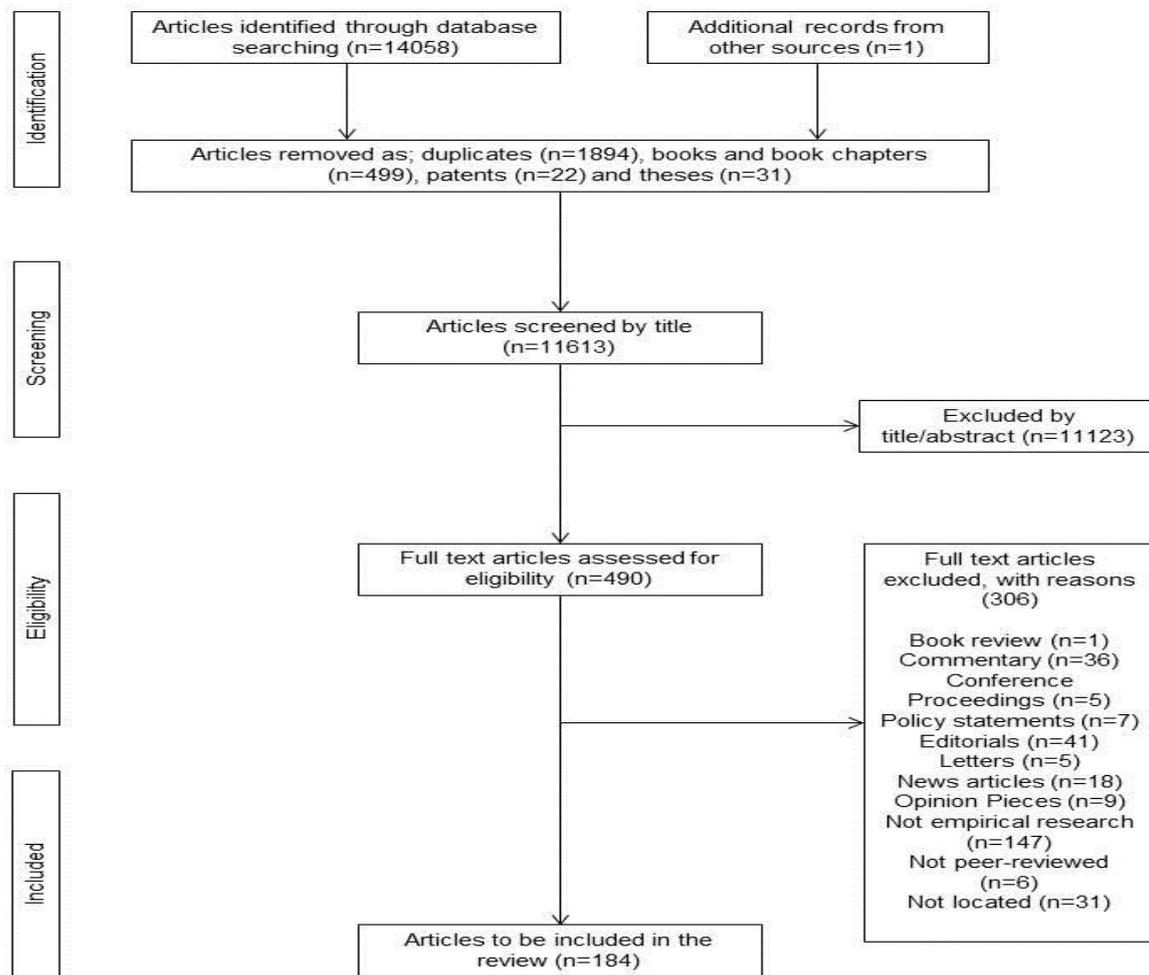
Regions were characterised along continental lines, with the 'non-continental' Caribbean grouped with South America. Papers which solely focussed upon the global level rather than a particular region were described as 'global'. The term 'global' is used where worldwide relevance is suggested, whereas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

### **Quality appraisal**

Due to the scale of the review, as well as the diverse study designs which were included, no formal quality appraisal was undertaken. Instead, decisions regarding the quality of research were made by reviewing study designs as per the hierarchy of evidence.<sup>lxxviii</sup> 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 palliative care research, where ethical issues surrounding randomisation and the inclusion of vulnerable groups in research limit the occasions where such trials are appropriate.<sup>xxix</sup> Nevertheless, as global health policymaking continues to become more evidence-based, it was deemed appropriate to consider the type and strength of study designs being used in international palliative care research.<sup>ii</sup>

The full process of study identification is presented in the flow diagram [Figure 5].

**Figure 5: Identification of relevant studies**



**Data extraction**

A total of 184 studies met the study inclusion criteria. Each included study is referred to as an output. Data were extracted from all outputs using a data extraction form, which was piloted to ensure that all relevant data were captured. The outcomes extracted are reported in Table 6. Additionally, due to the large amount of studies included, aggregated outcomes are presented and the full reference list of included studies can be found in Appendix 2.

**Table 6: Outcomes Extracted from Included Studies**

- 
1. Year of publication
  2. Journal of publication
  3. Region(s) of output focus
  4. Region of First Author of output
  5. Study design. Eg; cross-sectional, randomised controlled trial etc
  6. Thematic focus of output
- 

It is accepted that using First Author to indicate *Lead* author is something of a crude measure of determining leadership on a project and thus attributing research to a region. Different academic disciplines have different conventions relating to authorship. In Sociology, for example, the highest prestige is given to the First Author<sup>xxx</sup>, whereas, in Biomedical Science, the senior author, or research-group leader is commonly listed last.<sup>xxxi</sup> It was agreed that this was nevertheless a useful indicator of where research emanates from and would be extracted.

Before proceeding to give an overview of the data analysis and synthesis processes, it is first appropriate to acknowledge, that all decisions taken with regards to study identification involve the active role of the researcher. Therefore, the following section considers the risk of bias within the review.

### **Risk of bias**

It was recognised (and regrettable) that non-English language papers were excluded from the review. The resources available to the author did not permit the use of translational services. It is accepted therefore that this may introduce some geographic and language bias to the study. However, no non-English articles were identified and excluded, so this risk of bias was deemed minimal. Nevertheless, future researchers are urged to search in a wide variety of languages in any future update to this review.

Additionally, 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. Specific medicines used in

palliative medicine were not searched for individually. This approach is in 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 been included in the review.

All decision-making processes took place collaboratively to ensure a reflexive approach to research data however, ultimately the author made all final decisions. Processes of dual-coding and eligibility assessment were used in order to increase the validity and reliability of findings, however again, in cases of any disagreement, final decisions were made by the author. Such processes increase the likelihood of replicability of the study, however, this was not the overall aim of this qualitative review and all findings should be approached with consideration of the overall methods used to develop them.<sup>xxxii</sup>

## **Data analysis**

Data analysis was conducted using a descriptive thematic method for data synthesis<sup>xxxiii</sup>. 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.<sup>xxxiv</sup> 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 study supervisor (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.

Papers were analysed descriptively and allocated into emergent thematic categories by reviewing abstracts and full texts. Themes were applied, based upon the primary focus of the output and then checked by a study supervisor (CG). The process was then repeated, refining the thematic categories

and then verified once more before being finalised. Findings were then summarised descriptively according to the themes identified during extraction.

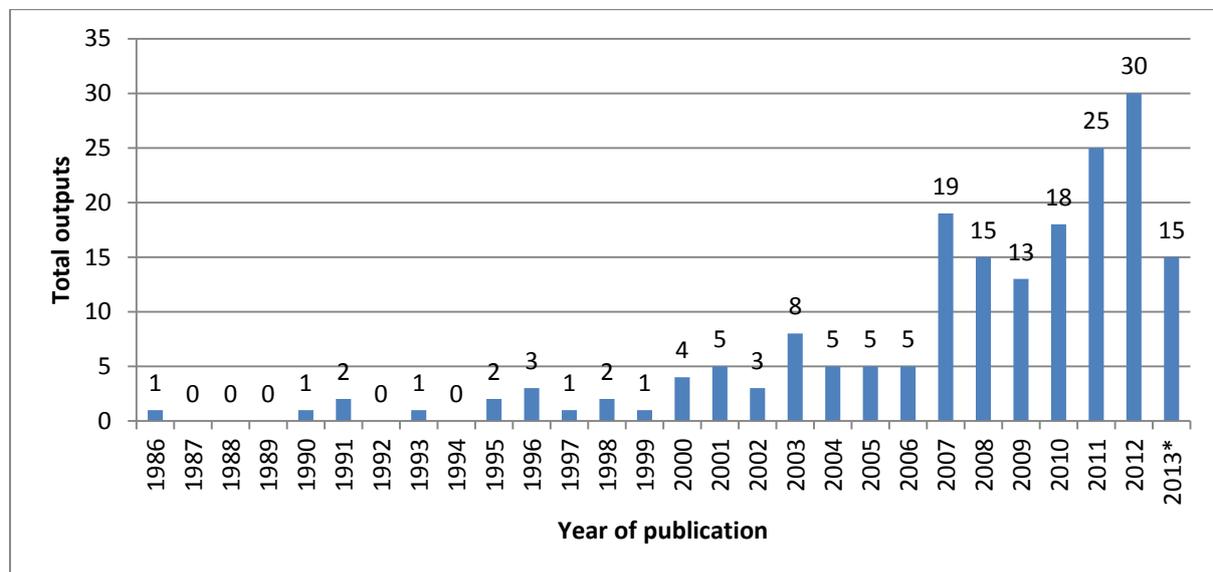
## Results

### Total outputs by year of publication

The earliest research paper identified on palliative care in an international context was published in 1986 (n=1) [Figure 6]. 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.

**Figure 6: Total outputs (n=184) by year of publication**



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.<sup>xxxxvxxvi</sup> 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 3 journals have published 10 or more outputs [Table 7], 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). 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.

**Table 7: Top 6 Journals which have published included international palliative care research articles**

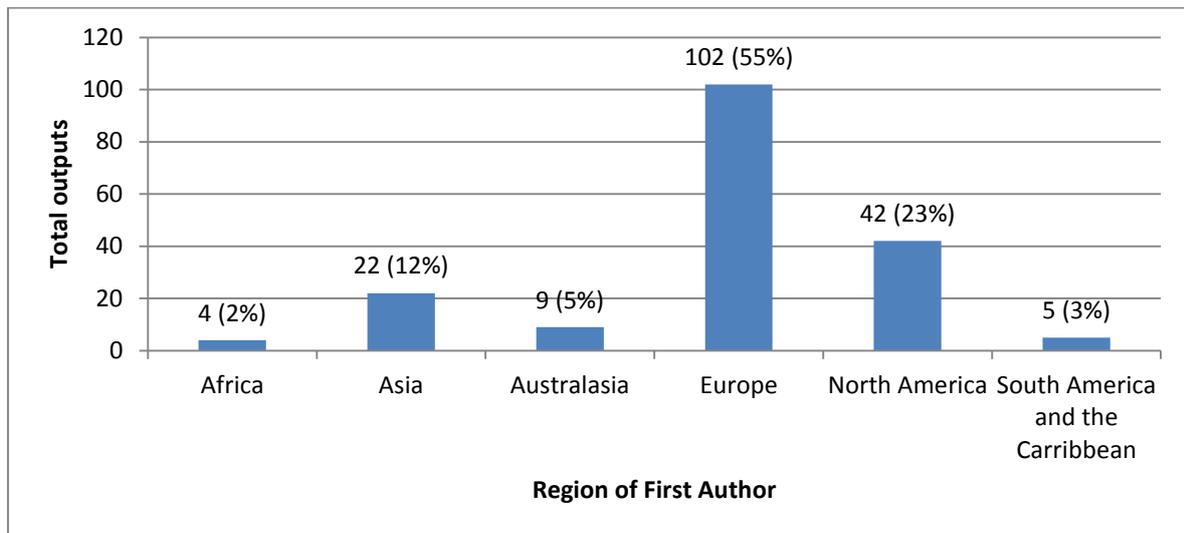
Journal title	Total
Journal of Pain and Symptom Management	39
Palliative Medicine	24
Journal of Palliative Medicine	10
Journal of Palliative Care	7
BMC Palliative Care	5
International Journal of Palliative Nursing	5

Nevertheless, there is only what can be considered a ‘critical mass’ of interest in palliative care in an international context (as reflected by included publications) in three journals – The Journal of Pain and Symptom Management (n=39), Palliative Medicine (n=24) and the Journal of Palliative Medicine (n=10). The ‘top-six’ journals which have published relevant outputs are shown in Table 7. It demonstrates drop-off in publication output from the two most prevalently publishing journals to the rest of the journals identified.

### Location of First Author

The location of the first author was extracted by noting the country in which the lead authors’ institution was located [Figure 7]. There was an uneven distribution in the geographical location of first authors who have published palliative care research in an international context.

**Figure 7: Location of first author based on home institution**

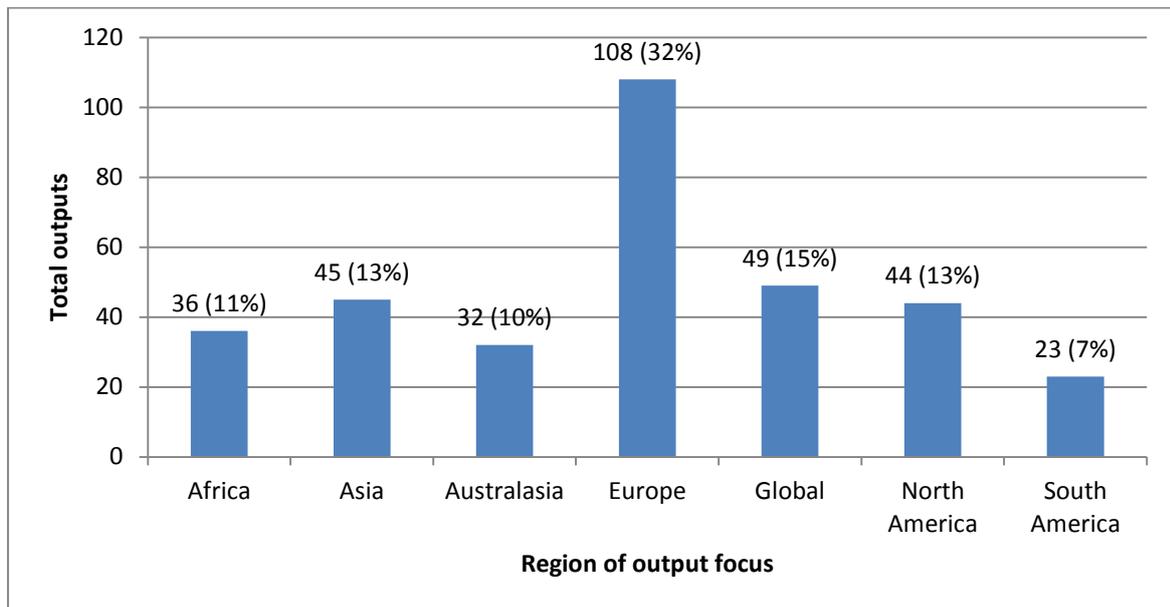


Using the country of the first authors' organization as an indicator reveals that 55% of international research originated from Europe, 23% from North America, followed by Asia, with 12%. The lowest levels of international research activity were found in Australasia (5%), South America and the Caribbean (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 [Figure 8]. Following this, 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.

**Figure 8: 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.<sup>xxxvii</sup> 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.<sup>xxxviii</sup>

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 overview**

Through descriptive analysis of included outputs, a total of 10 thematic groups emerged. The configuration each is presented in Table 8 and is followed by a synthesised analysis of each category with examples of studies included in each theme reported.

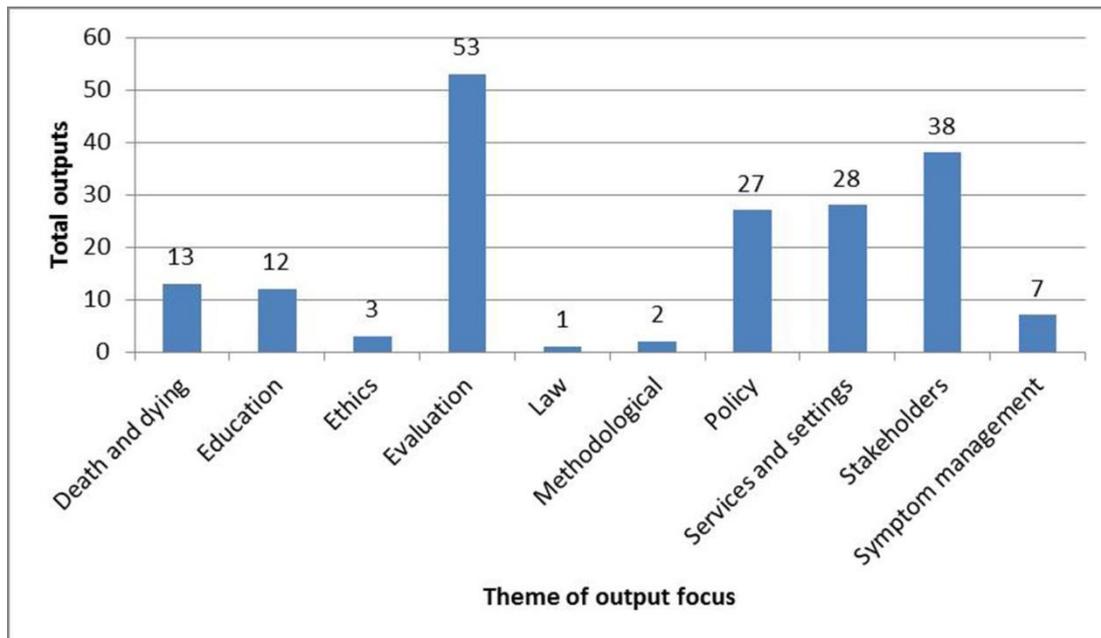
**Table 8: Overview of thematic categories (n=10)**

Theme	Description
Death and dying	Outputs focussing upon issues relating to death and dying – including assisted dying – from a palliative care perspective.
Education	Outputs focussed upon palliative care teaching, training, education and curricula.
Ethics	Outputs examining ethical issues relevant to palliative care, such as; decision-making, research practice and attitudes.
Evaluation	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	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	Outputs reporting on issues relating to methodology in palliative care research, including methodological challenges and opportunities in palliative care research.
Policy	Outputs reporting policy-level issues relevant to; standards, opioid availability, human rights, consensus building and international organization guidance etc.
Services and Settings	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	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	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 [Figure 9]. Stakeholders was the second most prevalent theme (n=38) with 21 % of the research focus. The third most researched theme, with 15% of the research focus, Services and Settings (n=28). Also with 15% of the research focus, was Policy (n=27). 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.

**Figure 9: Thematic focus (n=10) of included outputs (n=184)**



Whilst the scale of the review made it unfeasible to describe each study included within the review, the following sections provide an overview of the research focus within each thematic category. The full reference list of included studies is provided in Appendix 2. Each theme is here presented in order of total papers allocated to the category, from highest to lowest.

### **Evaluation (n=53)**

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).<sup>xxxix</sup> 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.<sup>xi</sup> 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.<sup>xii</sup> One study with broader relevance to the overall PhD

evaluated a morphine public health programme for cancer and AIDS pain relief in Sub-Saharan Africa<sup>xlii</sup>,

### **Stakeholders (n=38)**

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,<sup>xliii</sup> nurses,<sup>xliv</sup> patients,<sup>xlv</sup> and the general public.<sup>xlvi</sup> All such studies were conducted in circumstances where there *was* access to palliative care and none engaged with stakeholder groups in terms of considering consequences of lack of access to palliative care.

### **Services and Settings (n=28)**

Studies within this theme focus primarily upon efforts to map the existence of availability of palliative services internationally.<sup>xlvii</sup> Additionally, specific elements of palliative care are reviewed including; deep sedation<sup>xlviii</sup> GP home visits<sup>xlix</sup> and bereavement support.<sup>l</sup>

Also present within the theme was one study which considered access and equity of access in HIV/AIDS<sup>ii</sup>, disease-specific palliative care as well as another which considered the particular challenges of providing care to rural populations.<sup>iii</sup>

### **Policy (n=27)**

Many studies within this theme focussed upon issues such as access to essential medicines,<sup>liii</sup> consensus-building,<sup>liv</sup> barriers to the development of palliative care<sup>lv</sup> as well as articulations of clinical standards in palliative care.<sup>lvi</sup> One study demonstrated the lack of recognition from the broader medical establishment in Europe regarding palliative care as a medical specialty<sup>lvii</sup>, whilst another considers regulatory barriers which exist in Europe which serve to limit access to pain medications.<sup>lviii</sup>

Interestingly, no included study considered palliative care in terms of broader health care priorities such as the Millennium Development Goals. Nor did the review identify any study considering the

international relevance of palliative care models within universal health coverage health systems such as Costa Rica and Australia.<sup>lix</sup>

### **Death and Dying (n=13)**

This theme included significant focus upon cultural beliefs regarding death and the end of life<sup>lx</sup>, often presented comparatively between different nations.<sup>lxi</sup> Another specifically focussed upon the idea of death being a cultural taboo.<sup>lxii</sup> Other studies engaged with similarly intangible concepts, such as 'meaning' in terms of the transition towards end of life care.<sup>lxiii</sup> No included article considered palliative or end of life care in terms of its relationship (or non-relationship) with assisted dying or euthanasia.

### **Education (n=12)**

This theme revealed instances of collaborative international educational efforts including the use of teleconferencing as a mechanism for educational delivery<sup>lxiv</sup> as well as a report on the implementation of an international education program in Tanzania.<sup>lxv</sup> Although a relatively low number of studies were identified within the theme, almost all focussed upon the transferral of educational initiatives from one circumstance to another, including a participatory knowledge exchange, whereby the focus of the study was an educational partnership between Canada and Chile.<sup>lxvi</sup>

### **Symptom Management (n=7)**

Limited research attention was identified in terms of international research of symptom management. However, of the included studies, the most prominent symptom considered was types of pain, specifically cancer pain<sup>lxvii</sup> and breakthrough pain<sup>lxviii</sup> Other symptoms considered were fatigue<sup>lxix</sup> as well as other physical and psychological symptoms.<sup>lxx</sup> Additionally, one study focussed upon trends of opioid consumption between nations to demonstrate the ongoing inequality of access to pain relief between nations.<sup>lxxi</sup>

### **Ethics (n=3)**

Few studies engaged with ethical issues relating to palliative care in international context. Those which did, considered ethics in terms of their cultural specificity<sup>lxxii</sup>, issues which emerge following the diagnosis of a terminal illness<sup>lxxiii</sup> and consideration of what ethics committees should require in order to grant access to death certificates for a study which aimed to compare medical decisions at the end of life between nations.<sup>lxxiv</sup>

No study identified took a broader view of ethical issues in terms of whether there is an international ethical prerogative to increase access to palliative care.

### **Methodological (n=2)**

Of only two studies which engaged with methodological issues in international context, one considered study design in terms of implementing an end of life care pathway<sup>lxxv</sup> and the other offered a methodological framework for conducting economic analyses in end of life care.<sup>lxxvi</sup>

### **Legal (n=1)**

The one study within this category analysed the respective laws of five countries in terms of how they enable, or limit, access to opioid medications with regards to international guidance from the World Health Organization (WHO) and the International Narcotics Control Board (INCB).<sup>lxxvii</sup> The inclusion of Texas as a state serves as a reminder that legal barriers can vary even within a single nation. However, surprisingly, no studies were identified which critique legal issues in terms of the suggestion that access to pain and palliative treatments should be considered a human right. This broad analysis has revealed several issues in terms of areas of research weakness and strength of international palliative care research. However, before proceeding to analyse further, issues which have emerged from the review, the following section presents a short overview of the *types* of research which have been conducted as well as their relative strength in terms of each study designs' position on the hierarchy of evidence.

## 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<sup>lxxviii</sup>. 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<sup>lxxixlxxx</sup> and only one economic evaluation.<sup>lxxxi</sup>

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.<sup>c</sup> 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.<sup>lxxxii</sup> 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 be 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 palliative care research networks are emerging, with researchers from different countries working collaboratively, through research projects such as the EURELD Consortium commissioned by the European Union.<sup>lxxxiii</sup> This is significant due to the potential held by international research networks to exert influence within policymaking processes identified in Chapter Three.<sup>lxxxiv</sup> For instance, EURELD conducted a study of physicians' attitudes towards end-of-life decisions comparatively between seven countries.<sup>lxxxv</sup> 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.<sup>lxxxvi</sup> 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 and assist with identifying issues of 'universal' interest 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,<sup>lxxxvii</sup> conducting research to international ethical standards<sup>lxxxviii</sup> regardless of national regulations and involving local people and researchers to ensure that research is participatory, with informed consent.<sup>lxxxix</sup> 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<sup>xc</sup> and the risks of imposing western norms in differing cultural contexts.<sup>xcii</sup> 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<sup>xcii</sup> and the legal and ethical difficulties regarding whether a surrogate can or should provide consent for subjects who lack decision-making capacity.<sup>xciii</sup>

The low level of experimental studies identified by this review suggests that national-level barriers which limit opportunities for palliative care research are being mirrored at the international level. For example, the low prevalence of patient-centred research suggests that ethical challenges relating to consenting dying people into research are not being met.

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 apparent 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 differences 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.<sup>xciiv</sup> 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.<sup>xcv</sup> Moreover, such agencies will disburse funding towards the achievement of UHC using 'results-based financing.'<sup>xcvi</sup> 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.<sup>lix</sup> 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.<sup>xcvii</sup> 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.<sup>xcviii</sup>

## 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'<sup>xcix</sup>, 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.

Indeed, although the review searches were conducted in 2013 – prior to agreement of the Sustainable Development Goals (SDGs) – no study identified, considers palliative care as part of Universal Health Coverage (UHC). This may help explain why there is no specific mention of palliative care within the SDGs on the basis that there is not an evidence base to demonstrate the feasibility of palliative care within UHC. For instance, countries such as Australia and Costa Rica have universal health coverage with palliative care a part of this.<sup>lix</sup> Such examples warrant research attention in terms of identifying how this has been achieved, any resultant benefits and indeed theoretical discussion about how such models may be appropriate in other settings.

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.<sup>c</sup> The low prevalence of RCTs suggests that questions remain regarding the appropriateness of this methodology in palliative care research<sup>ci</sup> in spite of increasing evidence that cluster randomisation can be an effective design for research in end of life situations.<sup>cii</sup>

Little evidence was identified to suggest that international palliative care researchers are reaching out to other disciplines and schools of thought, to consider how palliative care issues such as how

palliative care could be advanced by engagement with the right to die or anti-right to die movements. Both of which promote the necessity of high quality palliative care before such measures should be considered. Nor is there any international evidence to support claims that palliative care is part of the whole continuum of care, from prevention and through bereavement. What evidence is there that palliative care can contribute to *preventing* illness as well as mitigating its negative effects.

Finally, looked at through the lens of international research, claims from researchers that there is a global need for palliative care, are not backed up by studies demonstrating that further roll-out of services is what populations *want*. Additionally, whilst some research activity was identified as occurring in Hong Kong, no studies were identified which consider the whole of China. This is a considerable omission considering not only that China holds almost 20% of the world's population<sup>ciii</sup>, but that the country is known to have the highest gap between need and supply of palliative care services.<sup>civ</sup>

Overall these findings suggest that international palliative care research is contributing little in terms of the presentation of palliative care within broader discourses on health. The implications of this, as well as questions which have emerged from this review to inform the broader PhD study are considered below.

## **Conclusion**

This review has revealed that international palliative care researchers are not maximising opportunities for further development by failing to produce evidence which is likely to engage with new global funding agencies. Given the opportunities to present palliative care as an important element of universal health coverage within the SDGs, it is of concern that no studies were identified which examined national models of UHC to determine their wider applicability. Additionally, the lack of research demonstrating the economic viability and feasibility is of serious concern, particularly when we consider the importance to which funding agencies are ascribing to 'results-based financing'. National level studies have shown how serious illness can plunge families into poverty in low-income countries<sup>cv</sup> and as richer countries such as the United States.<sup>cvi</sup> In this regard, it appears that palliative care researchers are continuing to miss opportunities, to consider the role which palliative care may be able to play in reducing such financial burden within the context of broader global health debates.

In Chapter Three, it was identified how processes of policy diffusion sometimes occur geographically and it was suggested that such narratives overlook the key role played by palliative care champions in spreading palliative care practices. However, it was also suggested, that characterising the spread of policy based upon geographic proximity alone is not a convincing explanation for the spread of palliative care. Instead, it was argued that more usually it is ‘similar’ countries which adopt ‘similar’ policies.<sup>cvii</sup> In this regard, existing narratives of development have considered such issues simplistically, attributing ‘similarity’ to financial factors such as Gross Development Product (GDP) only.<sup>xlvi</sup> Furthermore, studies included within this review present models of palliative care in different settings and profess their applicability to other similar settings for the same financial reasons.<sup>cviii</sup>

However, if palliative care is to be included as part of UHC, it must do so within the context of other development challenges facing nations. In this regard, it is too simplistic to characterise nations based upon level of income only and the broader national circumstances in which palliative care has (and has not) developed is not known. On this basis, the following chapter aims to enrich understanding of how palliative care practices have spread through an examination of the structural circumstances in which they have done so. Moreover, answering the question of whether ‘similar’ countries have developed palliative care ‘similarly’ will allow increased understanding of the transferability of ‘model services’ to other settings.

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## Chapter Six

# From Which National Development Contexts have Palliative Care Services Emerged?

### Introduction

In Chapter Two, existing narratives of palliative care development were considered with a focus on the related International Observatory on End of Life Care (IOELC) and Worldwide Palliative Care Alliance (WPCA) studies as the only global maps of palliative care services.<sup>iii</sup> The linked studies offered several explanatory factors for the international spread of palliative care including ‘increases in awareness and desire to improve care for the dying’. Furthermore, in Chapter Three it was identified how it appears that palliative care has developed to some extent in geographical clusters, for instance in Sub-Saharan Africa [Figure 3].

Geographic clustering of policies and practices is consistent with World Society Studies theory regarding policy diffusion. World Society Scholars suggest that practices such as palliative care spread naturally, as nations become organized around shared principles and institutions, with such processes happening most prominently in regions of geographic proximity.<sup>iii</sup> However, this analysis was critiqued as being too passive and did not recognise the significant dynamic actions undertaken by ‘transfer agents’ such as Anne Merriman, who introduced palliative care into Uganda. Moreover, ‘natural diffusion’ does not account for differences in practices between nations, nor how geographically isolated countries such as Australia have developed palliative care to a high level.<sup>ii</sup>

On this basis, it was suggested that Global Social Policy (GSP) analysis of policy convergence occurring due to dynamic processes of lesson learning and policy transfer was more convincing.<sup>iv</sup> That is, policymakers facing ‘similar’ policy challenges look to other contexts in order to determine how other similar nations have formulated policy responses and consequently adopt similar policies. Such processes are said to occur most prominently between countries which are ‘similar’.<sup>v</sup> In this regard, Chapter Five identified several studies which described ‘model services’ in varied income resource-contexts, with study authors making claims that such models may be transferrable to other ‘similar’ settings.<sup>vi</sup>

However, in such studies, what wasn't described was what it means for countries to be considered 'similar'. Indeed similarity was characterised economically only, though the complexity of terms such as 'low-resource setting' was not addressed. Furthermore, the WPCA study offers little to increase understanding in this regard. Few statistical indicators relating to countries' level of development were included, and were not adequately problematized or theorised in terms of potential relationships with palliative care development. For instance, Human Development is reported in relation to palliative care development, however, specific elements of this composite indicator are not considered, nor why they may be relevant to palliative care. Furthermore, a focus purely upon financial context belies other challenges to the delivery of healthcare in diverse settings, for example ensuring access to services for rural populations.<sup>vii</sup>

On this basis, this chapter presents a descriptive analysis of the national contexts from which palliative care services have (and have not) developed. International Organizations (IOs) collate a wide range of country indicators relating to international development. Using such indicators, it is possible to present a detailed analysis of the contexts within which policymakers operate, in terms of key development opportunities and challenges.

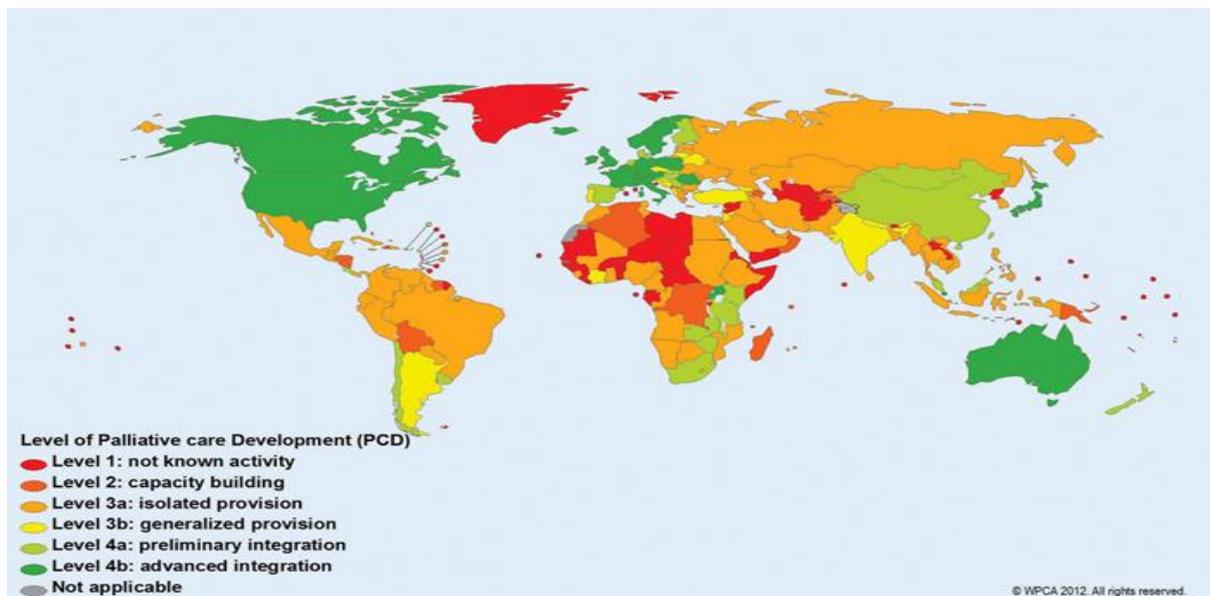
### **Rationale for the study: The international spread of palliative care services and practices; policy learning, diffusion and transfer**

The WPCA's global map of palliative care demonstrates that palliative care services can now be found in all world regions [Figure 10]. Additionally, it shows that the highest concentrations of development are to be found in high-income settings. This raises questions regarding why, when studies identified in the review suggest that palliative care roll-out is feasible in all resource-contexts, have services developed so patchily?

Existing narratives of development have emphasised the key role played by 'champions' as well as the significant role played by international pioneers. As identified in Chapter Two, Cicely Saunders is credited with the establishment of the modern hospice movement.<sup>viii</sup> Other notable early pioneers include Elisabeth Kubler-Ross who introduced palliative care to the United States<sup>ix</sup> and Ann-Merriman who did likewise in both Singapore and Uganda.<sup>x</sup> Considering such personalities in terms of the policy learning literature, is to suggest that processes of international palliative care development and transferral of social norms has been driven by 'transfer agents', rather than broader global influences or policies.<sup>xi</sup>

Additionally, active educational initiatives and processes of lesson-learning emanating from ‘model services’ such as Hospice Uganda may be considered too dynamic to be termed ‘natural processes of diffusion’.<sup>xii</sup> Indeed, Hospice Uganda was established in order to serve as a ‘model for Sub-Saharan Africa’, therefore encouraging active processes of international lesson-learning may be considered as a part of its mandate.<sup>xcv</sup>

**Figure 10: Global Map of Palliative Care Development**



Source: WPCA, 2011<sup>i</sup>

Chapter Two showed how palliative care has developed *in spite* of a lack of global leadership. Therefore attention must be given to processes of policy learning and transfer *between* nations as opposed to the relationship between nations and global organizations to understand palliative care development to date. For instance, we may understand the concentration in richer nations in terms of ‘similar’ countries adopting similar policies.<sup>xiii</sup> That is that policymakers within such nations face similar challenges and thus look to other settings in order to consider potential policy responses.

Whilst geographical proximity at a practical level, makes the international transferral of ideas and convergence of practices through transfer agents and other processes of lesson learning more straightforward, notions that proximity imply *similarity* are contested.<sup>xiv</sup> That is, geographic proximity does not necessarily mean that nations are similar in any domain, be it geographically, politically or in terms health system organization. On this basis, this chapter considers the structural

similarities and differences regarding the structural contexts within which palliative care services have (and have not) developed. For instance, it may be suggested that the celebrated model of community provision of palliative care in Kerala, India has developed *in spite* of the broader Indian context, where access to services remains extremely low.<sup>xlvii</sup> How then did such a model develop? Additionally, it is well known that Kerala has unexpectedly high social development indicators in relation to other Indian states, could it be that it was because of such contextual factors that such a service was able to emerge *in spite* of resource restrictions?

Whilst causal relationships between such factors are difficult to determine, this chapter considers such questions. Additionally, the suggestion that it is activities at national, rather than global level which have driven development, are placed under further scrutiny. Findings from the WPCA study included both testable and non-testable suggestions by using global indicators. For instance, the suggestions that development has been driven by ‘the practical needs of ageing populations’ may be considered by interrogating demographic indicators relevant to populations and ageing. However, factors such as ‘increased awareness of palliative care’ are less questionable using development indicators.<sup>ii</sup>

Without downplaying the achievements of palliative care champions such as Merriman, it is important to remember that services – and policies – are not formed within a vacuum. Alongside motivated individuals, what other factors have driven palliative care development? The current state of knowledge has not placed palliative care within broader structural processes of health care development. Moreover, researchers have not yet fully engaged with macro level data – collected by International Organizations such as the World Health Organization (WHO) and the World Bank – which may be relevant to the development of the field.

This study aimed to rectify these gaps in the knowledge base by examining the broader structural contexts in which palliative care has (and has not) developed to a high level.

## **Aims and objectives**

The aim of this chapter is to consider the structural contexts of nations based upon indicators of their development in relation to the extent to which they have integrated palliative care into their health care systems. A broad range of developmental indicators will be used in this regard to answer the following aim:

**Aim:** To determine in which national developmental contexts palliative care services have (and have not) emerged

In addition to meeting this broad aim, this study aimed to meet several further objectives:

1. To test policy learning assumptions regarding whether policies and practices are more likely to 'diffuse' geographically, or based on contextual similarity between nations.
2. To explore claims that palliative care is a feasible intervention in all world settings
3. To determine whether palliative care has developed to similar levels in countries which are 'similar' in terms of disease demographics, socioeconomics, and country demographics (eg has palliative care developed most significantly in countries which have predominantly urban or rural populations?)

## Methods

### Study design

In order to answer these questions and meet the objectives of the chapter, a quantitative design was used to explore potential relationships between predictor variables and level of palliative care development. Spearman's Correlation test was used to determine any observed linear relationships between structural variables and level of palliative care development which were unlikely to be due to chance. The outcome variable (level of palliative care development) was the WPCA country classifications from 2011, selected as the only usable data which determines rankings for all world countries.<sup>ii</sup> Predictor variables were selected iteratively using a theoretical approach drawing from several macro-datasets including the World Bank Development Indicators,<sup>lxvii</sup> the Economist Intelligence Unit (EIU)<sup>xv</sup> and Transparency International.<sup>xc</sup>

It is recognised that *direct* cause and effect influence over development would have been difficult to identify, however the methods used do not seek to establish causal relationships between variables. Instead the study provides descriptive examination of the structural contexts within which services

have developed to add to understanding of the circumstances in which palliative care services and practices have developed.

In order to identify variables of potential interest, a theoretical approach to understanding palliative care and healthcare development was adopted and will be outlined in terms of variable selection. However, before considering which variables may have been of interest, it was important initially, to identify what data are available in the public domain in order to meet the aims and objectives of the study. The first step was to identify the outcome variable and consider the validity of this indicator itself.

### **Outcome Variable: level of palliative care development**

As identified in Chapter Two, in recent times researchers have attempted to map both the global development of palliative care as well as to assess the quality of its provision. In 2010 the Economist Intelligence Unit, ranked the ‘quality of death’ of 40 countries, an exercise repeated and extended in 2015 to include 80 countries.<sup>xv</sup> However this study is limited by its inclusion of less than half of the world’s countries or areas, and only the Worldwide Palliative Care Alliance (WPCA) study has mapped *global* levels of development, the results of which are the focus of this section.<sup>ii</sup>

The WPCA study reports the level of development in the ‘234 countries or areas’ as defined by the United Nations (UN) on a six-point scale. The overall typology of country groups is presented in Table 9 and the full characteristics of each group are presented in Appendix 3. A discussion follows here regarding the validity of the WPCA’s conclusions as well as the methodological approach used to formulate them.

In Chapter Two it was identified how these country groupings are somewhat subjective and that the methodological approach used to determine them had limitations. For instance, there was reliance upon ‘key experts’ within nations to determine their own countries’ ranking, which is associated with a risk of information bias.<sup>xvi</sup> Further questions were raised regarding the validity of some of the rankings including Uganda’s due to conflicting assessments found by the Economist Intelligence Unit’s study examining quality of care, which gave the country a low ranking.<sup>xvii</sup> Indeed, the EIU ranked Uganda, a country the WPCA considers to have achieved full integration of palliative care into its health system, below Mexico, a country which the WPCA characterises as having only ‘isolated palliative care provision’ only.

**Table 9: Typology of country groups**

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<b>Country group</b>	<b>Recoded category</b>	<b>Characteristics of group</b>
Group 1	1	No known hospice-palliative care activity
Group 2	2	Capacity building activity
Group 3a	3	Isolated palliative care provision
Group 3b	4	Generalised palliative care provision
Group 4a	5	Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision
Group 4b	6	Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision

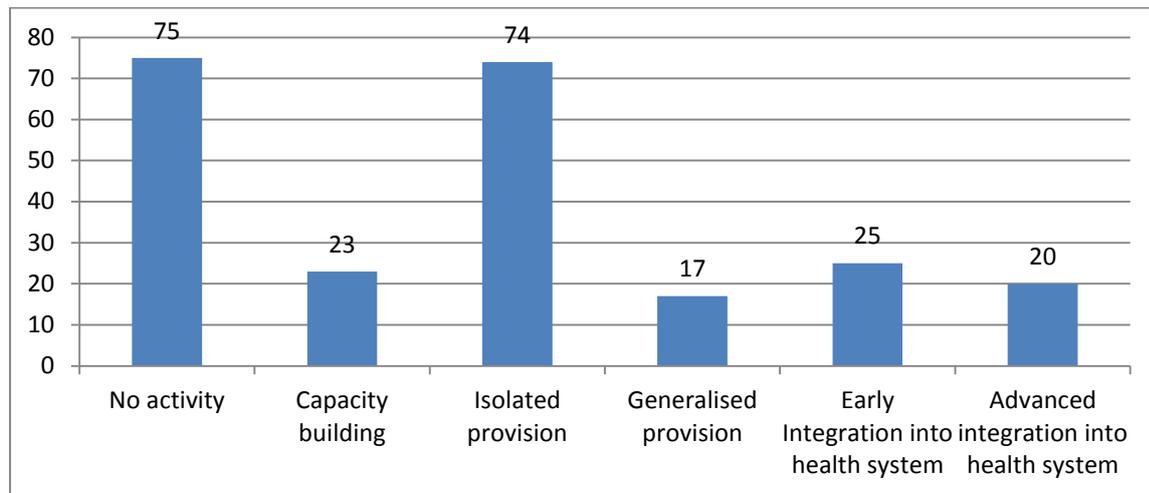
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These discrepancies urge caution whilst using the WPCA country group classifications. However, in spite of the methodological limitations of the WPCA study, their results remain the only *global* index of level of palliative care service development and as such their categorisations were used as the dependent variable. It is also important to note, that in spite of the methodological limitations identified, the WPCA rankings has been widely adopted and cited by organizations including the WHO.<sup>xxiii</sup>

#### **Levels of international development by country category: descriptive statistics**

As described in the previous section, WPCA country rankings were determined in 2011 by drawing upon a wide range of data and then categorised into groups. As the typology used by the WPCA included two-point categories (e.g. 4a and 4b), therefore, country groups were recoded into continuous ordinal data on a six-point scale [Table 9]. The distribution of countries within each recoded category is shown in Figure 11.

**Figure 11: Distribution of countries by level of palliative care development**



An uneven spread of palliative care development is revealed and it is of concern that ‘no known activity’ is the most prevalent group.

It is important to acknowledge that ordering the variables as an ordinal scale presented a problem for analysis. Some models assume a metric in which it is the same ‘distance’ between adjacent groups which is unlikely to be the case.<sup>xviii</sup> For example, to move from Group 1 (no provision) to Group 2 (capacity building) is likely to be more straightforward, than moving from Group 3b (generalised provision) to Group 4 (preliminary integration into mainstream service provision). Therefore the conclusions which were drawn from this ordinal scale were largely narrative and did not seek any predictive value. In addition it was deemed appropriate to use the ordered scale without applying any weightings to the country categories.

### **Theoretical approach to variable selection**

In order to give some focus to the identification of potentially relevant variables, a theoretical approach was undertaken to identifying variables of interest.<sup>xix</sup> Based upon guidance identified in Chapter Two from the WHO that a public health approach should be taken to palliative care development<sup>xx</sup>, the first domain considered for potential relevance focusses upon measurable aspects of such an approach. The WHO recommendations suggest that a public health approach to palliative care, should work within the ‘culture, disease demographics, socioeconomics and health care system of a country.’ Therefore, the distinct aspects of a public health approach are here considered separately, followed by other domains of theoretical interest.

## Disease Demographics

One of the key arguments that advocates use for a greater roll-out of palliative care services, is that there is a *global need* for palliative care.<sup>xxi</sup> Chapter Five revealed an overall absence of a patient-voice in terms of what their 'needs' may be at the end of life. We are therefore, left with technocratic arguments that there is a *normative* need for palliative care based upon disease prevalence.<sup>xxii</sup>

Therefore, figures for what the level of need for palliative care is, are based on calculated estimates of global disease prevalence rather than public demand for services. The illnesses the WHO considers may benefit from palliative care listed for both children and adults are as follows:

**Adults:** Alzheimer's and other dementias, cancer, cardiovascular diseases (excluding sudden deaths), cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, drug-resistant tuberculosis (TB).

**Children:** cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies (excluding heart abnormalities), blood and immune disorders, HIV/AIDS, meningitis, kidney diseases, neurological disorders and neonatal conditions [p.10].<sup>xxiii</sup>

More generally, it is often stated that palliative care is appropriate for both non-communicable (NCDs) and communicable diseases (CDs).<sup>xxiv</sup>

The Bank and the WHO collected total deaths by country in only 2000 and 2012. Whilst both of these dates fall outside of the five-year period specified, the information was deemed *too relevant* to disregard and as such, an exception was made to the date range to include the 2000 figures on total deaths by CDs and NCDs.

Although there is now recognition that palliative care is beneficial for sufferers of NCDs *and* infectious illnesses,<sup>xxv</sup> it is only since 2002 that this has been recognised within the WHO definition.<sup>xxvi</sup> Therefore one line of enquiry within this study was to examine whether the vast amount of financing from the Millennium Development Goal (MDG) era towards infectious diseases has furthered palliative care development.<sup>xxvii</sup> Therefore, deaths from communicable and non-

communicable diseases (as a percentage of total deaths) were included as independent variables for analysis.

### **Socioeconomics indicators**

Socioeconomic factors are some of the key predictors of health, at global, national and individual levels.<sup>xxxviii</sup> Whilst advocates maintain that palliative care is feasible and deliverable in all resource contexts, a glance at the global distribution of palliative care services is enough to show that services are concentrated in richer nations [Figure 10].<sup>xxix</sup> Yet, notable examples of celebrated services do exist in poorer regions, such as the Neighbourhood Network of Palliative Care (NNPC), in Kerala, India, a community-led service which is considered replicable model for the rest of India and the developing world.<sup>xxx</sup> Kerala is, however, vaunted for more reasons than palliative care development having achieved many social indicators more akin to a more highly developed country than the rest of India.<sup>xxxi</sup> High life expectancy and literacy rates form the context from which the NNPC has emerged, suggestive of a link between social indicators and palliative care development.

### **Health systems**

Calls for a public health approach to be taken to palliative care development, sit alongside the 2014 WHA Palliative Care Resolution calling for palliative care should to be fully integrated into health systems.<sup>xxxii</sup> Yet, in Chapter Two, it was identified that many palliative care services operate outside of formal healthcare systems.<sup>xxxiii</sup> On this basis, a broad conceptualisation of the term ‘health system’ was adopted to incorporate informal services and understand a health system as:

The combination of resources, organization, financing and management that culminate in the delivery of health services to a population [1991].<sup>xxxiv</sup>

This definition acknowledges that ‘many factors outside the health system influence people’s health, such as poverty, education, infrastructure, and the broader social and political environment’.<sup>xxxv</sup> Understanding health systems in these terms therefore requires a much broader conceptualisation of factors which may influence health system performance. One such explanation, describes health systems as ‘complex adaptive systems’, where *nonlinear* relationships between different factors interact over multiple scales, which often produce unexpected outcomes.<sup>xxxvi</sup> Using this definition, roads, for example, may be part of this ‘system’, as without them, access to healthcare is likely to be

compromised<sup>xxxvii</sup>. Their presence, however, may also contribute to new health problems such as respiratory illness due to increased cars and pollution, as well as increased traffic accidents. Questions also arise regarding whether there have been different levels of development between publicly funded or private health care systems.

Viewing palliative care as part of complex health systems provided justification for a broad approach when considering how palliative care services may have developed and led to a widening of approach beyond a focus purely upon a public health approach to development. For instance, political context and country demographics are circumstances within which all health policy decisions are made.

The following section therefore considers other domains which are known to have influence over public health more generally: political context, country demographics and economic factors.

### **Political context**

An apparent absence from the recommended public health approach to palliative care is consideration of the influence of political factors over healthcare development.<sup>xxxviii</sup> Political ideology and policies form the context within which health systems function and develop. Informed by a study which used political ideology as part of an analytical public health framework, inferences may be made regarding government commitment to healthcare based upon levels of spending relative to countries' wealth.<sup>xxxviii</sup> Additionally, there have been links drawn between *strength of democracy* and health outcomes – regardless of a country's wealth, level of inequality or the size of its public sector.<sup>xxxix</sup> More generally, it is suggested that countries which have fewer inequalities are likely to have better health outcomes.<sup>xl</sup> As such, health systems and services cannot be separated from the 'political context' in which they operate. 'Political context' was therefore added as a theoretical domain from which to include variables.

### **Country demographics**

Each nation of the world faces different challenges to delivering healthcare based upon the demographic make-up of the country. In epidemiological terms, 'demography' is defined as:

The study of populations, especially with reference to size and density, fertility, mortality, growth, age, distribution, migration, vital statistics and the interaction of these with social and economic conditions.<sup>xli</sup>

Such factors occupy much discussion within discourses on palliative care. Specifically in terms of : ageing populations<sup>xlii</sup>, mortality rates<sup>xliii</sup> and the challenges of delivering services in rural areas.<sup>xliv</sup> Such factors are added to the related socioeconomic indicators discussed above and variables were drawn from this domain [Table 12].

### **Economic indicators**

The final domain which was included in the analysis is concerned with countries' economic context. Gross National Income (GNI) is considered a key component of a countries' human development.<sup>xlv</sup> Further, a nations' wealth is a strongly associated with health outcomes of its people.<sup>xlvi</sup> Additionally, richer nations provide financial assistance to poorer nations to fund healthcare through Official Development Assistance (ODA), though it is not known the extent to which this has had an impact upon palliative care development. Whilst advocates argue that palliative care delivery is feasible in all resource contexts<sup>xlvii</sup>, the extent to which nations' wealth or levels of ODA received have had an influence over levels of palliative care service development is not well understood.

The theoretical underpinning of this study therefore, emanated from the domains of socioeconomics, disease demographics, health care systems, politics, demographics and economics. Although this conceptualisation of theoretical factors relevant to health is inclusive, it is not exhaustive. Indeed, for reasons of feasibility, it was necessary to be selective, with the types of variables included in the study. The following section outlines therefore, other theoretical domains which were considered for inclusion in the study, but excluded as unfeasible.

### **Variable domains considered and excluded**

#### **Cultural factors**

This study recognised that cultural appropriateness is an essential element of effective palliative care delivery.<sup>xlviii</sup> However, due to the high diversity within any ecological data relating to culture, it was

decided that cultural indicators were unlikely to be a useful explanatory indicator to use within the model. This decision was guided by understanding culture as:

A set of shared and enduring meaning, values and beliefs that characterize national, ethnic, or other groups and orient their behaviour [1991].<sup>xlix</sup>

Attempting to apply such a definition to a whole nation, would have been extremely problematic. That is, in the globalised world we live in, where processes of migration have seen diverse populations living in countries across the world, it is difficult to ascribe a single set of cultural beliefs – and therefore indicators – to a single nation.<sup>i</sup> Therefore, when ‘public health approach’ recommendations that palliative care should be rooted in the ‘culture’ of a nation, it must be acknowledged that there will be competing definitions and understandings of what a ‘national culture’ means, particularly in relation to beliefs and practices relating to death and dying.<sup>ii</sup> For instance, in Australia, studies showing which suggest a patient-preference for a home death<sup>iii</sup>, do not adequately incorporate a desire from aboriginal people to die in their traditional lands, which may not be their current ‘home’ as the term is more generally understood.<sup>liii</sup>

Accordingly, attempting to formulate culturally-appropriate policies even within countries is challenging. Extrapolating this challenge to the formulation of global level policies is even more so. Therefore, whilst it is acknowledged that delivery of palliative care must be culturally sensitive, no indicators of ‘culture’ were included as independent variables.<sup>liv</sup>

## **Religion**

The history of palliative care is not complete without consideration of the role of religion in its development.<sup>lv</sup> Considered the first modern Hospice, St Christopher’s itself, carries it with it implicit associations with Christianity. The incorporation of spiritual care by Cicely Saunders into her conception of ‘total pain’ also recognised the importance of religion in peoples’ lives and particularly at the end of life.<sup>lvi</sup> That religion continues to play a role in the development of palliative care services is not in dispute. Certainly faith-based organizations continue to promote and establish palliative services.<sup>lvii</sup>

However, without diminishing the historical and ongoing contribution of religious groups to promoting palliative care, here, religious indicators were not included in the analysis. In part, this is

as global policymaking organizations such as the UN profess to develop policies using a secular approach.<sup>lviii</sup> Furthermore religious diversity around the world makes it difficult to determine what 'religion' a country is. A clear example, for instance is India, which is commonly considered a Hindu country, but in reality is highly diverse, for instance, there are approximately 172 million Muslims in India, a number which would rank as the eighth most populace country in the world.<sup>lix</sup> Therefore, due to this heterogeneity it was deemed inappropriate to ascribe a single religion to any one country. Additionally it is known that Christian missionary groups from Europe have played an active role in introducing palliative care into other settings (eg Africa), national indicators of religion would not adequately represent such processes.<sup>lx</sup> Therefore, indicators of religion were not included in this analysis, although the study recognised the importance of including spiritual care within palliative services to people of all denominations as well as to people of no faith.

### **Identifying independent predictor variables**

The next stage of the study was to identify development indicators of potential interest as the independent variables. Several International Organizations (IOs) collate international development indicators including the World Bank and the UN. Therefore, before identifying potential variables of interest, it was first appropriate to consider data which is available to ensure that the study was feasible, before focussing upon potential variables of interest.

### **Available data sources**

International Organizations – such as the WHO and the World Bank – collect macro data on development indicators, available in the public domain. A major challenge of this study was to isolate the variables for inclusion in the project which may have relevance to palliative care development and broader health care systems. On this basis, consideration of potential variables to be included began from an acceptance of the Bank's conceptualisation of health which acknowledges that:

Many factors outside the health system influence people's health, such as poverty, education, infrastructure, and the broader social and political environment [2007].<sup>lxi</sup>

This definition is useful as it acknowledges the varied ways in which context influences health. For instance there are known associations between poverty and higher rates of both infectious and non-

communicable illnesses.<sup>lxii</sup> Accordingly, understanding ‘health’ in this manner, necessitated consideration of a wide range of variables which *may* have provided the context within which palliative care services have developed.

Due to the broad range of development indicators collected by the World Bank (n=1327), it was decided that the World Bank’s databank would be the starting point for variable selection. Although the WHO and the Bank share data sources, the selection of the Bank’s data reflects its self-applied status as the ‘Knowledge Bank’ with the resources to collate a huge amount of development indicators comparatively.<sup>lxiii</sup> Moreover, the Bank’s data has been widely used by researchers in order to analyse levels of development of nations comparatively, for instance in domains such as social welfare.<sup>lxiv</sup> In any event, there is much crossover between the data. Both organizations use the same data for ‘total deaths by cause’ for instance.

The headings listed by the World Bank of their development indicators offer some insight into the broad range of data available (Table 10).

**Table 10: Development data categories collected by the World Bank**

Agriculture & Rural Development	Economic Policy & External Debt	Environment
Health	Poverty	Science & Technology
Aid Effectiveness	Education	Financial Sector
Infrastructure	Private Sector	Social Development
Climate Change	Energy & Mining	Gender
Labor & Social Protection	Public Sector	Urban Development

Source: World Bank Data, 2013<sup>lxiii</sup>

Broadly speaking, the World Bank collect ‘each’ year from national governments and other international agencies<sup>lxv</sup>, though there is a high amount of missing data. The reasons for missing data are varied and include; sporadic data collection by countries, lack of data reporting due to conflicts or lack of statistical capacity and simply because as national borders are redrawn, new countries

emerge whilst others cease to exist.<sup>lxvi</sup> In addition, as much of the data collected is collated from the statistical systems of member countries, data quality is heterogeneous and reliant upon the performance of national systems.<sup>lxvii</sup> Data is available from 1960 onwards.

### **Other data sources**

Whilst the range of data collected by the World Bank is comprehensive, it is not exhaustive and to capture the full range of potentially relevant macro-level data, other sources were identified informed by both palliative care and GSP literature. The International Narcotics Control Board (INCB), for example, collects country-level data on opioid consumption per capita which is collated by the Pain and Policy Studies Group and is likely to be relevant to palliative care.<sup>lxviii</sup> Additionally, civil-society institutions produce and collate global level data of potential theoretical interest. For instance, Transparency International measures levels of corruption within countries<sup>lxix</sup>, whilst the Economist Intelligence Unit, ranks the international strength of democracy by country which serve as an indicators of political context.<sup>lxxxvi</sup>

### **Data cleaning and selection**

Having considered developmental domains of theoretical interest to the study, the next phase of the study was to isolate variables of potential interest using an inductive approach within selected theoretical domains. This involved the development of hypothetical reasons, rooted in palliative care literature, why individual variables may be relevant to palliative care development. On this basis, the following section describes how variables were selected drawing upon the theoretical domains selected for analysis based upon the availability of data.

The first stage of data cleaning was to ascribe a palliative care score to all countries for which there is World Bank data. Therefore the full spreadsheet of development indicators was downloaded, with the appropriate palliative care score entered to matched countries.

Of the 234 countries and territories assigned a palliative care rating by the WPCA, only 207 had a matching country classification with the World Bank [WB] due to ongoing territorial disputes and different conceptualisations of sovereignty. For example, the WB groups the channel islands, whereas, the UN lists Guernsey, Jersey etc separately. On this basis, 27 'countries and territories' were removed from the sample and are reported in Appendix 5. All countries and territories

removed had a palliative care development rating of between 1 and 3. In reducing the country sample from 234 to 207, the broad story told by the distribution is changed only slightly [Table 11]. Group 3 (Isolated provision) becomes the mode instead of Group 1 (no known activity)

**Table 11: Total countries in each country group before and after removal of unmatched countries.**

Country Group	Frequency (n=234)	% of countries in group	Total removed from each classification group	Frequency (n=207)	% of countries in classification group
1	75	32	17	58	28
2	23	10	4	19	9
3	74	32	6	68	33
4	17	7	0	17	8
5	25	11	0	25	12
6	20	9	0	20	10

After this ‘matching’ process between UN and World Bank country classifications, the final country sample for analysis was 207. The full list of countries included within the analysis as well as their palliative care ranking and study number is presented in Appendix 6. The greatest challenge for data cleaning, was to address the problem of missing data. It was decided that data would only be included for the five year period up to and including 2011, the year that the outcome variable data was collected. This five year period was selected through discussion with palliative care (CG) and statistical expert (MC) as reasonable time-free from which to make reasonable associations between palliative care development and broader developmental context. However due to the sporadic nature of data collection, some exceptions were made to this approach. For example, in line with the theoretical importance of disease demographics and health systems, data from 2000 was included as this was the only available date collected prior to 2011.

### **Limitations of the data**

As with all studies of this nature, the conclusions which can be drawn from the results of the analysis, must be tempered with caution, due to the limitations of the data used to form them. Having critiqued the reliability of the WPCA country groupings, in this section, the complications of analysing national level data comparatively are presented when different mechanisms have been used in order to compile the datasets.

In essence, this study aimed to compare the structural contexts of countries, to isolate variables which may have led to (or been led by) palliative care development. Thus, it was important to consider methodological issues relating to international comparative research as well as what can be learned from comparative research.

International comparative research can be conducted to determine, analyse and explain similarities and differences across societies.<sup>lxx</sup> An immediate observation regarding the comparability on the dependent variable, would be that although there are only 6 country categories, sharing a category with another country, does not make the palliative care systems in those countries *the same*. Instead, they have achieved a shared ranking. Problems regarding the validity of these rankings were discussed above, however accepting the scores as the best available data, countries within each category can be deemed comparable.

A key insight that can be offered by comparative research is to develop ‘robust generalizations’ – a necessary component of developing effective global policies.<sup>lxxi</sup> Yet, this study did not intend to isolate a ‘golden variable’, one which provides a ‘pathway’ for how palliative care development should be enabled. Instead, it aimed more modestly, to describe the national contexts within which palliative care has, and has not, developed.

The major challenge to this study of using international data comparatively was the comparability of the data itself. As recognised, the World Bank relies on country-collected data which raises a whole range of issues for the researcher. These issues include, but are not limited to homogeneity of data samples, completeness of data, both within countries and as reported to the World Bank and competing definitions<sup>lxxii</sup>

In this sense, all of the variables included in the analysis had flaws. However, the use of one outcome variable derived from a single study, allows us to consider countries within each country grouping as ‘comparable cases’.<sup>lxxiii</sup> Thus, the use of an ordinal scale allows us to consider what *other* characteristics are shared between countries within each country grouping.

With regards to the independent variables, it was deemed impractical to consider the risks of biases within each variable between all countries. Therefore, the risk of bias across countries was considered equal and in spite of the limitations of the data, this study followed other researchers in using such data on the premise that it is the ‘best available’.<sup>lxxiv</sup>

After gaining understanding of the wide range of variables available, the next phase of the study was to refine potential variables of interest using a theoretical approach. On this basis, the following section describes the process that potentially relevant structural indicators were identified, through consideration of theoretical understandings of palliative and health care development.

### **Variable selection**

Having considered the available data and appropriate theoretical domains from which variables of interests may be drawn, a scoping exercise was undertaken of World Bank data in order to consider the hypothetical relevance of variables using an inductive approach, drawing from the data categories presented in Table 10. This involved reviewing available data and considering indicators in terms of whether a theoretical argument could be constructed for their inclusion as an indicator of palliative care development. In this manner, it was straightforward to include indicators such as percentage of total deaths due to communicable diseases [Table 12] in order to consider questions such as ‘has palliative care benefitted from high levels of global funding for infectious diseases?’ Similarly, it was clear that many variables collected by the Bank had no theoretical relevance to palliative care, for instance ‘Methane emissions (kt of CO<sub>2</sub> equivalent).’<sup>lxxxv</sup>

Once a full review was undertaken, this process was reviewed by a palliative care expert (CG). In cases of disagreements regarding the inclusion of variables, such instances were resolved through discussion and based upon the strength of a theoretical argument for the inclusion of any given variable. Final decisions were made by the author. In this manner, additional variables such as ‘strength of democracy’ were added to the sample based upon the theoretical approach to variable selection described. In this instance a strong known link between strong democracies and good health of populations.<sup>xxxix</sup>

A full list of the 28 final agreed predictor variables can be found in Table 12 along with the theoretical domain from which they were selected. A full description and detail of each variable as well as a theoretical reason for the inclusion of each is presented in Appendix 4.

Data for potentially relevant indicators was imported into SPSS and the most recent indicators within the five-year period 2007-2011 were consolidated. In many circumstances, data was not available for each indicator to match the full sample of countries. When this occurred, missing data were

removed from the analysis and the total countries included in each correlation are reported in Appendix 4. This process was documented, listing the years of data included for each country as the total number of countries for which there was data for any given indicator.

**Table 12: Included independent variables (n=28) by theoretical domain**

<b>Predictor variable</b>	<b>Theoretical domain</b>
Cause of death, by non-communicable diseases (NCDs) (% of total)	Disease demographics
Cause of death, by communicable diseases (% of total)	
Life expectancy at birth, total (years)	Socioeconomic
Age dependency ratio (% of working-age population)	
Literacy rate, adult total (% of people ages 15 and above)	
Out-of-pocket health expenditure (% of total expenditure)	
Death rate, crude (per 1,000 people)	
Prevalence of undernourishment (% of population)	
GINI index	
International tourism, number of arrivals	
Internet users (per 100 people)	
Consumption of morphine equivalent in mg per capita	
Hospital beds (per 1,000 people)	
Health system ranking	
Health expenditure, public (% of GDP)	Political context
Health expenditure, private (% of GDP)	
Corruption index	
Public spending on education, total (% of GDP)	
Strength of democracy	Country demographics
Population ages 65 and above (% of total)	
Mortality rate, infant (per 1,000 live births)	
Urban population (% of total)	
Birth rate, crude (per 1,000 people)	
Mortality rate, adult, male (per 1,000 male adults)	
Mortality rate, adult, female (per 1,000 female adults)	
Population growth (annual %)	Economic indicators
GINI per capita (constant 2005 US\$)	
Net ODA received per capita (current US\$)	

## Relationships between predictor variables and level of palliative care development

Following the inductive approach to variable selection described, using Spearman's Correlation test, several variables (n=28) were tested for their relationship with the outcome variable [Table 12]. Spearman's correlation test was selected due to its known appropriateness for examining ordinal outcomes. The significance level was set at 5%, therefore any  $p < 0.05$  was considered statistically significant. This was not adjusted for multiple comparisons, because the p-value was regarded only as a guide. Most variables from the Bank were numerical data and were determined to be 'scale' data in SPSS, as they are ordered categories with a meaningful metric.<sup>lxxvi</sup> Life expectancy at birth is an example of a 'scale' variable. Also selected for analysis, were ordinal variables, such as Corruption, which was limited to scores between 0 and 10. Boxplots were also plotted to demonstrate where there were outliers, that is, points which are 1.5 times the interquartile range above the upper and below the lower quartile. The analysis of the strength of relationships between variables used the rule of thumb presented in Table 13.

**Table 13: Interpretation of correlation coefficient**

Value of correlation coefficient (r)	Strength of association
1	Perfect
$0.9 < r < 1$	Very Strong
$0.5 < r \leq 0.9$	Strong
$0.3 < r \leq 0.5$	Moderate
$0 < r \leq 0.3$	Weak
0	Zero

Source: Cohen L, 1992<sup>lxxvii</sup>

When considering any potential relationships between the variables, it was not assumed that significant association meant causation between the dependent and independent variables. That is, it is not suggested that any specific independent variable has had a *direct* influence over development. Instead, independent variables are used to add richness to understandings of the contexts within which palliative care services have developed. Further, no assumptions were made

regarding the nature of any relationships.<sup>lxviii</sup> That is, it is not inferred that independent variables have causality with the dependent variable, or vice versa. An illustrative example would be with regards to morphine equivalent consumption levels. Without additional information, it is not possible to infer whether higher levels of consumption have driven palliative care development, or whether, higher development has driven higher consumption. Furthermore, it was due to such uncertainty that regression analysis was not completed, in that it would be too simplistic to suggest that an increase in any single variable would have a clear effect upon level of palliative care development. Additionally, as the aim of the study was not to produce a predictive model of variables which *predict* levels of palliative care development, a wide range of variables were able to be included to enrich narrative analysis. Moreover, practical issues relating to the availability of data, would have reduced the size of the potential country sample in terms of palliative care development which was not in line with the aims of the study

## **Results**

Informed by the theoretical domains identified above, a total of 28 variables were included in the analysis drawing upon development data from the World Bank area and other data sources [Table 14]. To reiterate, hypothetical reasons were determined for the inclusion of each variable and are presented in Appendix 4. For instance, it may be suggested that given the historical association between palliative care and cancer, that countries with a higher proportion of NCDs may be more likely to have developed palliative care.

Using all available data, Spearman correlations were calculated, the results of which are presented below along with the domain from which variables were selected [Table 14].

**Table 14: Relationships between independent variables and level of palliative care development**

Domain	Independent variables	Correlation coefficient	P-value
Disease demographics	Cause of death, by non-communicable diseases (% of total)	0.529	<0.001
	Cause of death, by communicable diseases (%of	-0.481	<0.001
Socioeconomics	Life expectancy at birth, total (years)	0.445	<0.001
	Age dependency ratio (% of working-age	-0.324	<0.001
	Literacy rate, adult total (% of people ages 15 and	0.272	0.001
	Out-of-pocket health expenditure (% of total expenditure on health)	-0.158	0.031
	Death rate, crude (per 1,000 people)	0.152	0.032
	Prevalence of undernourishment (% of population)	-0.049	0.591
	GINI index	-0.259	0.001
	International tourism, number of arrivals	0.684	<0.001
	Internet users (per 100 people)	0.471	<0.001
Health systems	Consumption of morphine equivalent in mg per	0.587	<0.001
	Hospital beds (per 1,000 people)	0.301	<0.001
	Health system ranking	-0.418	<0.001
Political	Health expenditure, public (% of GDP)	0.362	<0.001
	Health expenditure, private (% of GDP)	0.129	0.078
	Corruption index	0.570	<0.001
	Public spending on education, total (% of GDP)	0.182	>0.025
	Strength of democracy	0.618	<0.001
Demographic	Population ages 65 and above (% of total)	0.524	<0.001
	Mortality rate, infant (per 1,000 live births)	-0.499	<0.001
	Urban population (% of total)	0.320	<0.001
	Birth rate, crude (per 1,000 people)	-0.447	<0.001
	Mortality rate, adult, male (per 1,000 male adults)	-0.346	<0.001
	Mortality rate, adult, female (per 1,000 female	-0.448	<0.001
	Population growth (annual %)	-0.218	<0.002
Economic	GNI per capita (constant 2005 US\$)	0.595	<0.001
	Net ODA received per capita (current US\$)	-0.376	<0.001

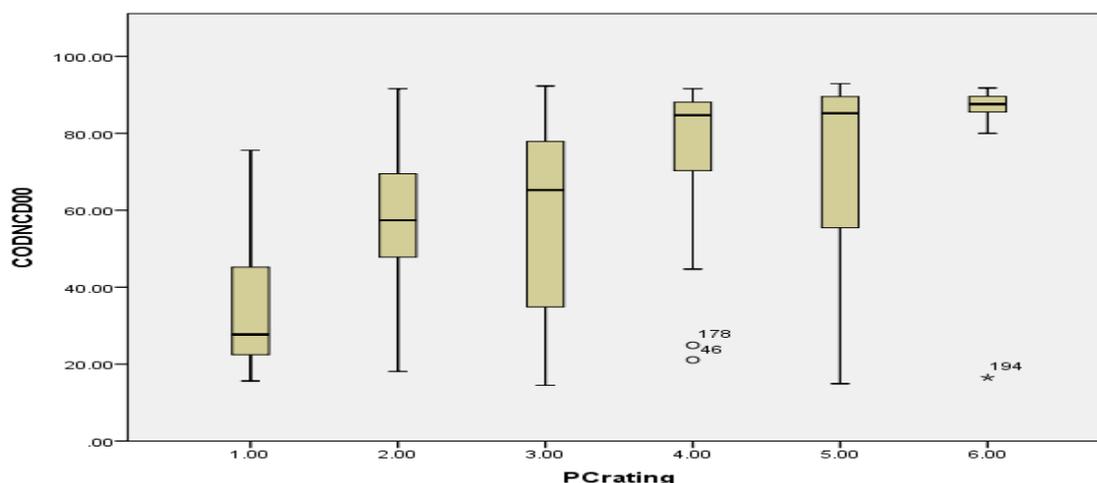
Of the 28 variables entered, only 2 did *not* have a significant relationship with palliative care development. Here relationships between the independent variables and level of palliative care development are presented. A short discussion follows the presentation of each theoretical domain.

## Disease Demographics

### *Cause of death, by non-communicable diseases (% of total)*

There is a strong positive relationship between the two variables ( $r=0.529$ ). This suggests that palliative care has developed most strongly in countries where NCDs are the primary causes of death. Further, it is shown that where less than 20% of deaths are from NCDs, it is likely that, those countries have no palliative care provision [Figure 12]. The relationship between the variables is however, not linear, with a greater percentage of deaths by NCDs in Group 4 countries than in Group 5, though we do find the highest number of deaths from NCDs in Group 6 countries.

**Figure 12: Boxplot examining the relationship between cause of death by NCD and palliative care development ( $r=0.529$ ,  $p<0.001$ )**

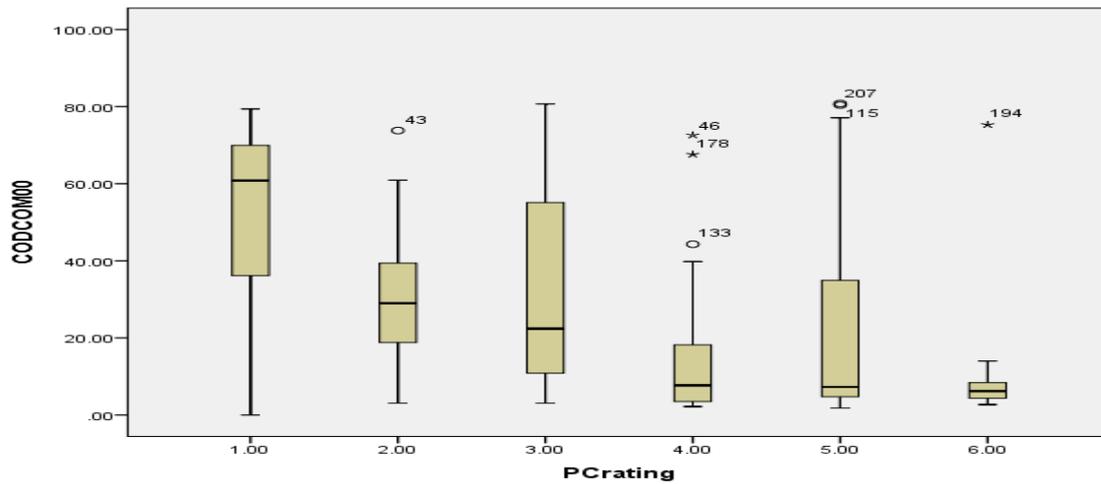


In Group 6, the outlier 194 is Uganda (194), where less than 20% of people die from NCDs, but which has achieved the highest level of palliative care development. In Group 4, Swaziland (176) and Papua New Guinea (46) have achieved generalised provision of services in a context of high levels of death from infectious diseases.

### *Cause of death, by communicable diseases and maternal, prenatal and nutrition conditions (% of total)*

A moderate negative relationship exists between the variables ( $r=-0.481$ ) which supports the finding that palliative care services have predominantly emerged to meet the needs of NCD patients.

**Figure 13: Boxplot examining the relationship between cause of death by communicable disease and palliative care development ( $r=-0.481$ ,  $p<0.001$ )**



In terms of outliers, in Group 5 (Zimbabwe (207) and Malawi(115)) and 6 (Uganda (194)) the indicate that these countries are exceptional to the broader trends and *have* developed palliative care to a high level in response to communicable diseases [Figure 13]. Overall, however in countries where most deaths are caused by communicable disease, palliative care services are less likely to have developed.

### **Disease demographics and palliative care development**

Palliative care services appear to have developed most in countries where NCDs represent the highest burden of disease. This finding supports narratives regarding the historical association between palliative care and NCDs, predominantly cancer. NCDs are the cause of most deaths throughout the world, with 68% of cases attributed in 2012. In Group 6 countries, the median percentage of deaths by NCDs is 88% compared with 27% in Group 1 Countries.

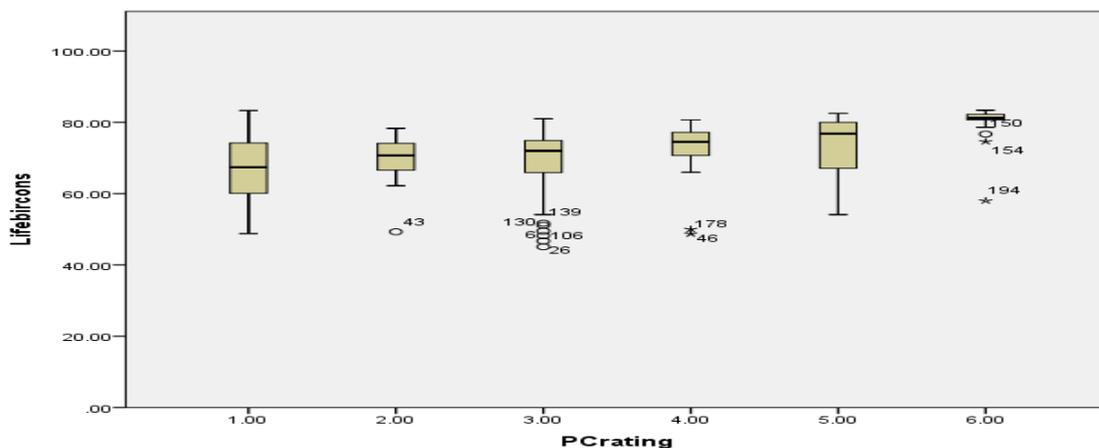
In this regard, globally speaking, it seems that developmental efforts aimed at tackling infectious illnesses have not incorporated palliative care alongside such efforts. An ongoing association between infectious diseases and poverty<sup>lxxix</sup> is also suggestive that services have developed predominantly to meet the needs of richer populations.

## Socioeconomic factors

### *Life expectancy at birth, total (years)*

There is a moderate positive relationship between the two variables ( $r=0.445$ ). This suggests that palliative care has developed most strongly in countries where people live longer. Viewing the boxplot [Figure 14], however, it is shown that in all but one country groupings there are countries with life expectancy of over 80 suggesting that increased life expectancy has not been a major driver of service development.

**Figure 14: Boxplot examining the relationship between life expectancy and palliative care development ( $r=0.445$ ,  $p<0.001$ )**

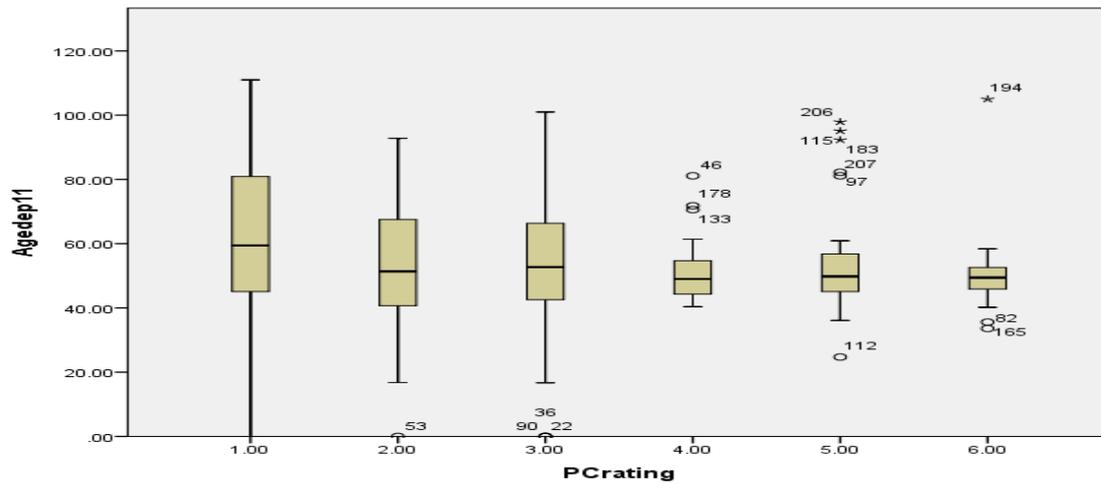


However, in Group 6 countries, the quartile range is highly concentrated around life expectancy of 80, with only two outliers (Uganda (194), Romania (154)). This supports the suggestion that palliative care has developed in countries where a high proportion of the population is likely to live into old age. Outside of Group 6, increased life expectancy seems to be less of a determinant of countries' palliative care development.

### *Age dependency ratio (% of working-age population)*

Age dependency ratio is a measure of the working age population in relation to people under 15 and over 64. The correlation coefficient ( $r=-0.324$ ) suggests a moderate negative relationship between the variables. The higher the ratio of dependents to working age people in a country is associated with lower levels of palliative care development [Figure 15].

**Figure 15: Boxplot examining the relationship between age dependency ratio and palliative care development ( $r=-0.324$ ,  $p<0.001$ )**

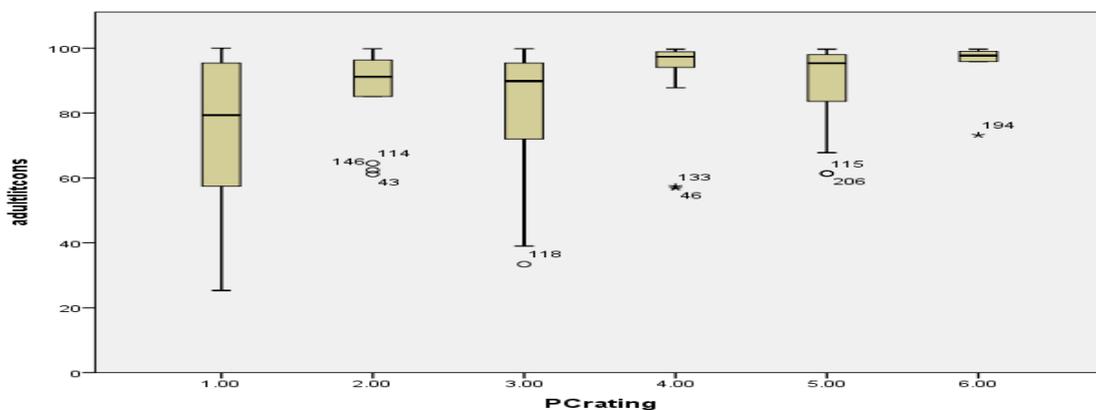


Whilst the boxplot is indicative of a high level of uncertainty regarding the relationship, the moderate negative association challenges the notion that palliative care has developed to meet the needs of ageing populations internationally. More likely perhaps, however is that it is the lower age bracket (people aged 0-15) is influencing this relationship. Instead it could therefore be suggested that palliative care has not developed where there is a broadly *young*, rather than ageing population.

***Literacy rate, adult total (% of people ages 15 and above)***

There is a weak, positive relationship between literacy rates and level of palliative care development ( $r=0.272$ )

**Figure 16: Boxplot examining the relationship between literacy rates and palliative care development ( $r=0.272$ ,  $p=0.001$ )**

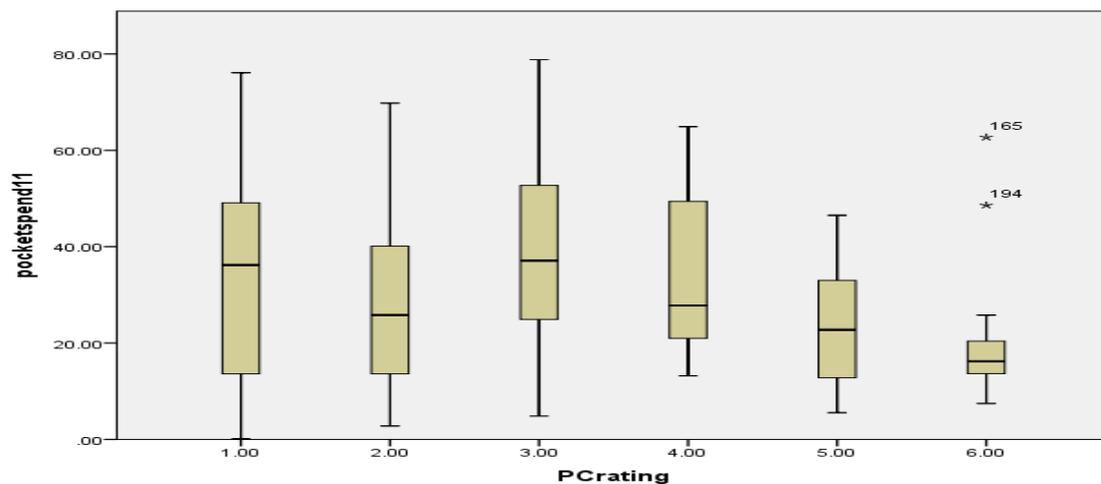


The weakness of this relationship is perhaps attributable to the overall high levels of literacy in the sample, making differences more difficult to detect [Figure 16].

### ***Out-of-pocket health expenditure (% of total expenditure on health)***

A weak negative association is shown by the correlation coefficient between pocket health expenditure and palliative care development ( $r=-0.158$ ). This suggests that in countries where more people pay for healthcare at the point of use, that palliative care services are less likely to have developed.

**Figure 17: Boxplot examining the relationship between out-of-pocket expenditure on health and palliative care development ( $r=-0.158$ ,  $p=0.031$ )**

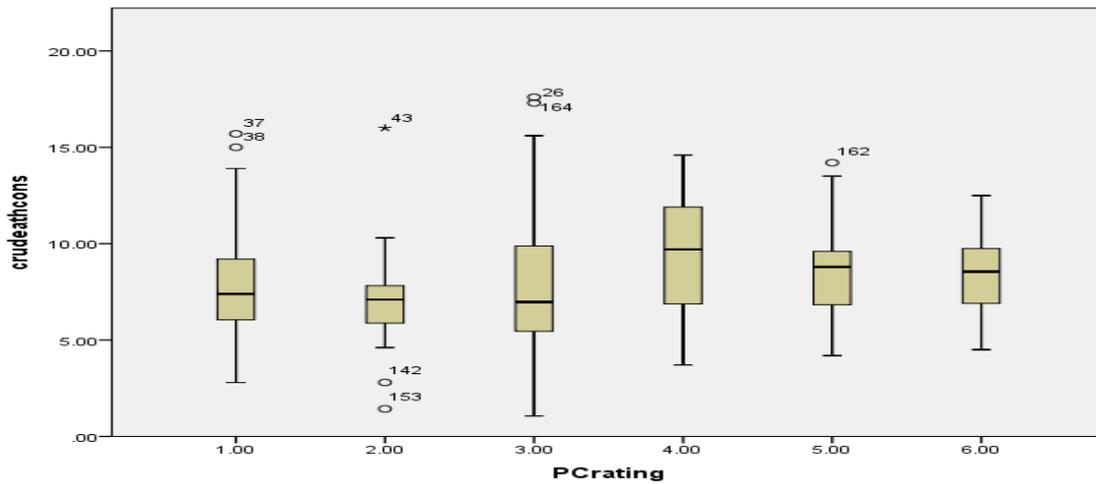


The boxplot however suggests no one overarching narrative of the relationship between the variables [Figure 17]. However it is noticeable that in Group 6 where the median out of pocket expenditure is lowest, the highest level of development is found. Uganda (194) and Singapore (165) are the only two outliers within the sample, where out of pocket expenditure is unexpectedly high in relation to level of development. The slight negative relationship between the two variables suggests that where people have to pay for healthcare treatment, that the trend is *not* towards expenditure on palliative services.

### ***Death rate, crude (per 1000 people)***

A weak positive relationship is revealed between crude death rates and palliative care development ( $r=0.152$ ). This casts doubt on the suggestion that palliative services have emerged to meet the needs of the dying.

**Figure 18: Boxplot examining the relationship between crude death rates and palliative care development ( $r=0.152$ ,  $p=0.032$ )**

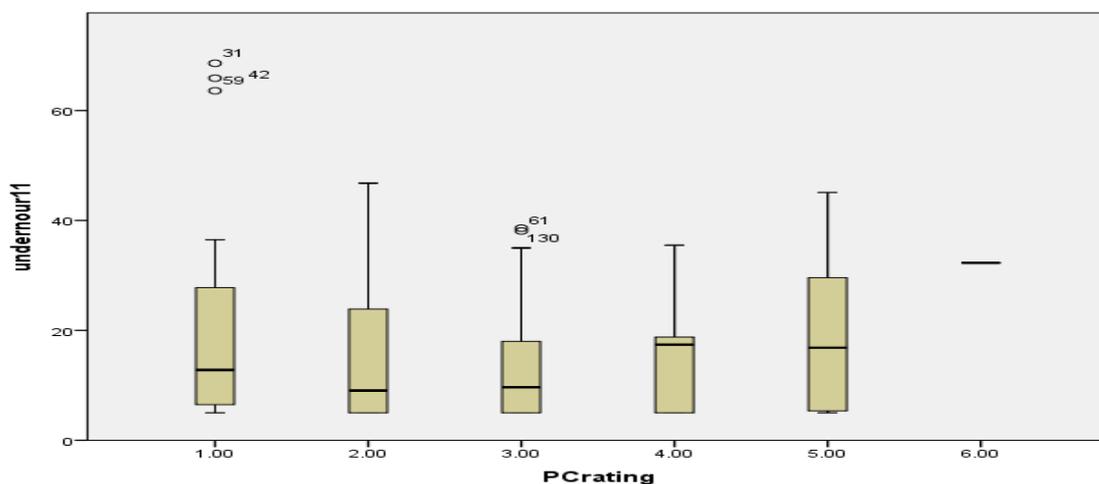


The boxplot demonstrates however, that there is no clear narrative to be made around the variables [Figure 18]. The highest median death rate is found in Group 4 countries and the median is higher in Group 6 countries than in Group 1. The result is suggestive of individual development experiences in different countries and does not support the idea that services have developed in response to prevalence of need.

***Prevalence of undernourishment (% of population)***

There is a very weak negative relationship between levels of undernourishment and palliative care development ( $r=-0.049$ ).

**Figure 19: Boxplot examining the relationship between prevalence of undernourishment and palliative care development ( $r=-0.049$ ,  $p=0.591$ )**

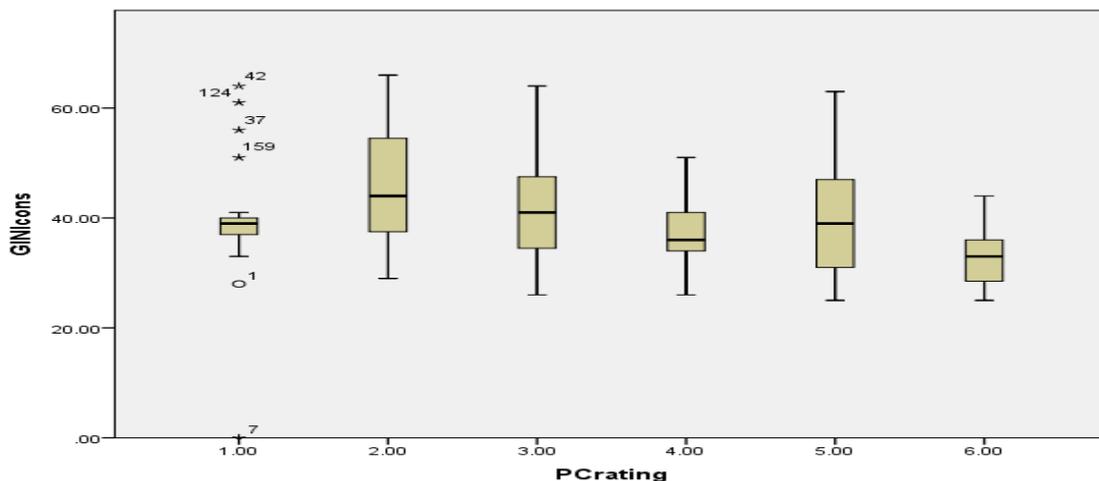


This relationship is neither linear, nor significant and the association is so weak that the variable may be disregarded as not relevant to the outcome variable [Figure 19]. Additionally, the World Bank does not currently collate data for undernourishment for countries such as the UK and the United States, which is why Group 6 appears to have higher than expected prevalence.

**GINI Index**

The GINI coefficient is a measure of income inequality within a nation [Appendix 4]. A weak, negative relationship with palliative care is demonstrated by the Spearman correlation coefficient ( $r=-0.259$ ). This is suggestive that in countries with higher levels of income inequality, that palliative care is less likely to have developed.

**Figure 20: Boxplot examining the relationship between level of income inequality within nations and palliative care development ( $r=-0.259$ ,  $p=0.001$ )**

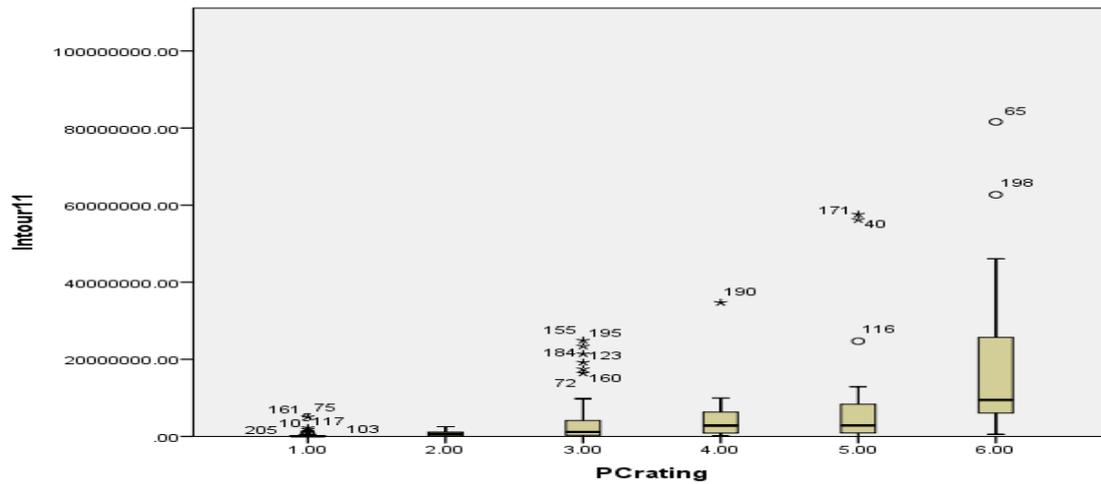


However, the weakness of the relationship – as well as the inconclusive evidence of a trend – means that firm conclusions regarding the association between these two variables are not possible [Figure 19]. There is the smallest suggestion that lower inequality within a country is linked to greater palliative care development, however, this conclusion should be treated with caution.

**International tourism, number of arrivals**

There is a strong relationship between the two variables ( $r=0.684$ ) suggesting that the more tourists that visit a country, the higher the level of palliative care development.

**Figure 21: Boxplot examining the relationship between total annual international tourism arrivals and palliative care development ( $r=0.684$ ,  $p<0.001$ )**

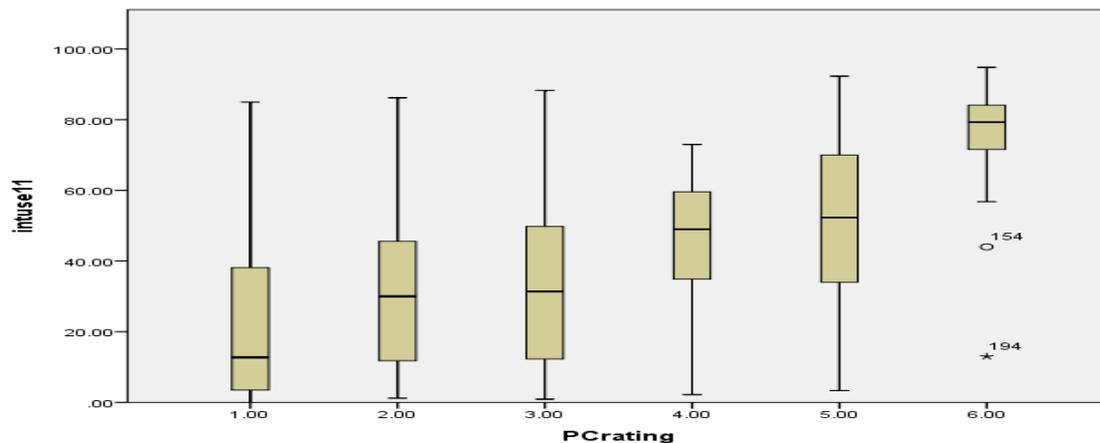


The high amount of outliers demonstrated by the boxplot however, suggest that this indicator should be understood with caution. However, as the boxplot shows [Figure 21], there is a clear trend towards countries with high levels of tourism having higher levels of palliative care development. This supports the suggestion that international tourism can lead to social policy responses in low-income settings.<sup>lxxx</sup> In this regard, it is also notable that there are very low levels of tourism in Group 1 and 2 countries alongside an absence of palliative care development.

***Internet users (per 100 people)***

The moderate positive relationship between the two variables ( $r=0.471$ ) appears to justify the inclusion of internet use as a variable. High internet use is associated with higher levels of palliative care development.

**Figure 22: Boxplot examining the relationship between levels of internet use and palliative care development  $r=0.471$ ,  $p<0.001$ )**



Once more Uganda (194) appears as an outlier along with Romania both of which have achieved high levels of service development in spite of relatively low internet use within the country [Figure 22]. Yet, this trend does not preclude that there may be high internet use amongst the palliative care community, which is not demonstrable through population level data.

### **Socioeconomic indicators and palliative care development**

Most socioeconomic indicators included in the analysis relate to palliative care in expected patterns. For instance, in countries where life expectancy is higher, palliative care services have developed to a higher level. This finding supports the WPCA analysis that palliative care services have developed in order to meet the needs of ageing populations. Additionally, that higher adult literacy rates and greater internet use are also features of countries with higher levels of service development, supports ‘access to education’ and ‘improved communication systems’ as factors which have influenced service development. Indeed tourism, the strongest relationship identified in this analysis (0.684) may also form part of the process of ‘broader support networks’ becoming established.

However, the ratio of dependents to working age people has a negative relationship with palliative care development. The greater the ratio between workers and dependents, the less likely that palliative care has developed. This finding challenged the hypothetical reasoning for including the variable and disputes the finding that palliative care has developed to meet the needs of ageing populations. However, there is a moderate positive relationship between population ages 65 and above (% of total) and level of palliative care development ( $r=0.524$ ). This means that the association between higher levels of dependents to working age people and its negative association with palliative care development may be explained by dependents consisting of predominantly *younger*

rather than older people. Furthermore, it is known that in many low-income countries that there is a high caregiving burden upon young carers.<sup>lxxxii</sup> It is not known however, the extent to which younger people caring for older dependents is attributable to societal norms or is due to practical realities in circumstances where there is no palliative care.

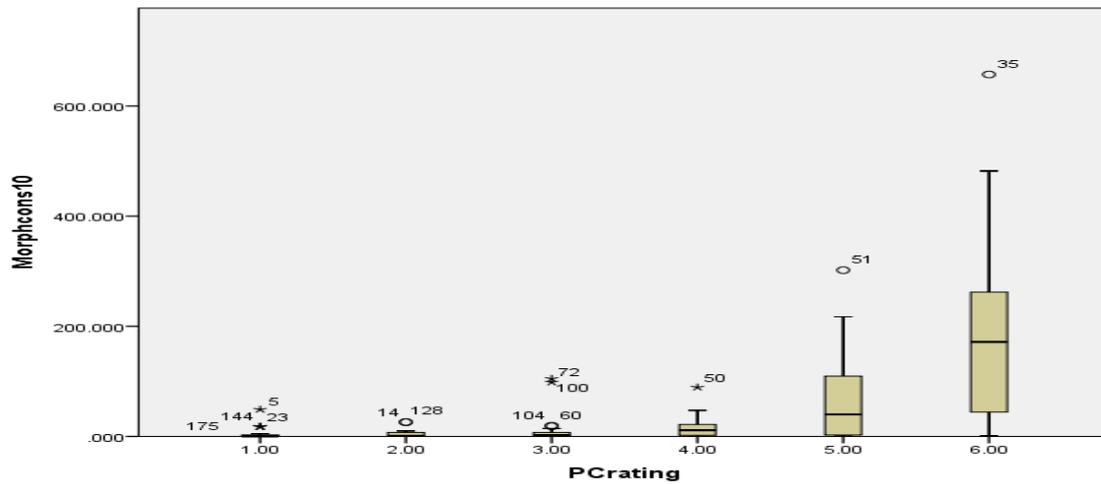
Additionally, poor socioeconomic outcomes were associated with lower levels of palliative care development in terms of low internet use and therefore decreased opportunities for lesson-learning. Furthermore, in countries where there is higher economic inequality between national populations, services are less likely to have developed. These indicators suggest *additional* developmental challenges within these countries which perhaps forms part of the explanation as to why palliative care services have not developed. However, it should also be noted that in countries such as the United States, income inequality is very high therefore caution should be used when associating income inequality with a countries' level of palliative care development.<sup>lxxxii</sup> However, it should also be noted that wealth is reported as a positive determinant of access to palliative care.<sup>lxxxiii</sup>

## **Health Systems**

### ***Consumption of Morphine Equivalent (ME) in mg per capita***

There is a strong positive relationship between ME consumption and level of palliative care development ( $r=0.587$ ) which suggests that global ME consumption is concentrated in countries which have higher levels of palliative care availability.

**Figure 23: Boxplot examining the relationship between Morphine Equivalent consumption and palliative care development ( $r=0.587$ ,  $p<0.001$ )**

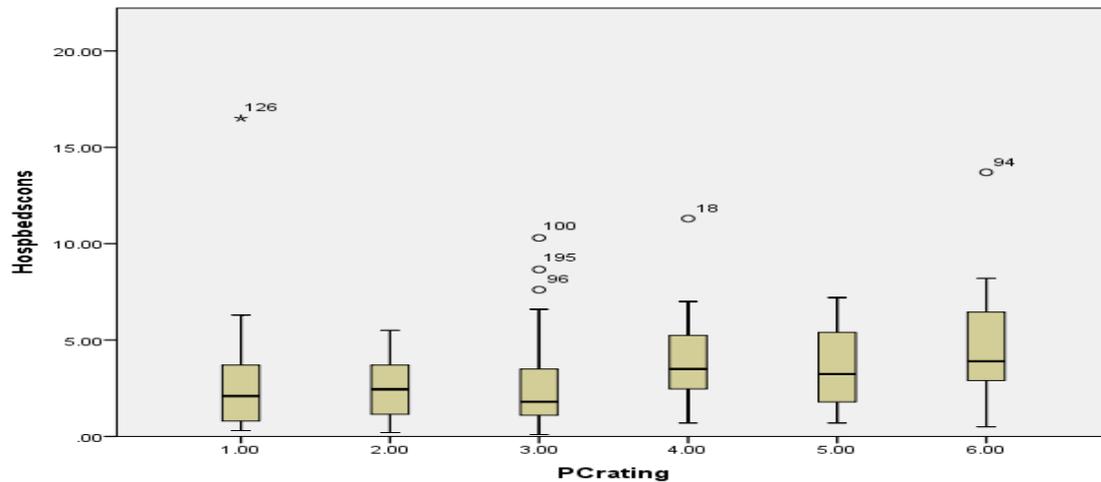


Although the relationship is only moderate, the boxplot demonstrates that ME consumption is highly concentrated in Group 5 and 6 countries [Figure 23]. However, morphine consumption remains very low in some countries within Groups 5 and 6. For instance there is a real difference in consumption between two Group 6 countries: in Uganda (194), consumption is 0.75mg per capita, in relation to Canada (35) where it is 657.27mg per capita. More generally, the boxplot shows a broad lack of ME consumption within country groupings 1-4, in which most countries of the world are located.

***Hospital beds (per 1,000 people)***

There is a weak positive association between hospital beds (per 1,000 people) and level of palliative care development ( $r=0.301$ ). This suggests that in countries in which there are more hospital beds available per person, that some of these may be being used for palliative care purposes.

**Figure 24: Boxplot examining the relationship between hospital bed per 1000 people and palliative care development ( $r=0.301$ ,  $p<0.001$ )**



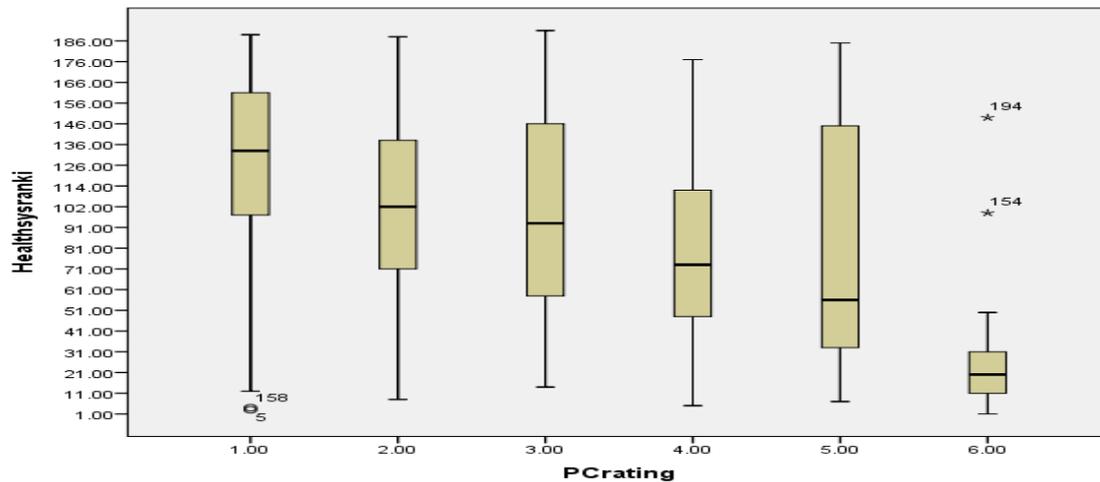
An extreme outlier in Group 1 is Monaco, which raises doubt regarding the territory’s palliative care rating [Figure 24]. It is difficult to conceive that a place with the highest ratio of people:hospital beds has no palliative care services at all. More generally, there is an uneven positive trend here, though the range of hospital beds per person appears similar across all groups. Group 6 has the highest median score of beds per 1000 people.

### ***Health system ranking***

This is a measure of health system strength in terms of; improvement in health, responsiveness and distribution of services.<sup>lxxxiv</sup> France (65) has the top rated health system and a low health system score is indicative of a strong health system.

There is a moderate negative relationship between health system strength and level of palliative care development ( $r=-0.418$ ). This indicates that stronger health systems are more likely to have developed palliative care services.

**Figure 25: Boxplot examining the relationship between health system ranking and palliative care development ( $r=-0.418$ ,  $p<0.001$ )**



The boxplot shows a clear trend, with weaker health systems associated with lower palliative care development [Figure 25]. Group 6 comprises most of the top-ranked country health systems. Two outliers in Group 6 (Romania (154), Uganda (194)), show relatively weak health systems, which have been able to achieve high levels of development *in spite* of this circumstance. Yet, there is high diversity within the sample and there are countries across all Groups which have highly ranked health systems.

### Health systems and palliative care development

Although the WHO's ranking of health systems occurred in 2000, there is evidence that palliative care has developed most effectively as an element of stronger health systems

In Group 6, Romania (154) and Uganda (194) were outliers in terms of health system strength. This supports pioneer-driven narratives of development, whereby services have developed to a high level in spite, or outside of the formal health care system. Indeed, Casa Sperantai in Romania, now considered a 'model service' began as one UK nurse and a single Romanian nurse<sup>lxxxv</sup>, whilst Dr Anne Merriman played a key role in the introduction of palliative care in Uganda.<sup>xcv</sup>

Linked to this, in countries where there are a greater proportion of hospital beds relative to the population, development was likely to be higher. However hospital beds (per 1,000 people) does appear to be a less clear indicator of level of palliative care development. Across Groups 1, 3 and 4 there are countries with a high proportion of beds relative to the population. In these countries, it

may be suggested, that little prioritisation has been given to palliative care in spite of available inpatient facilities.

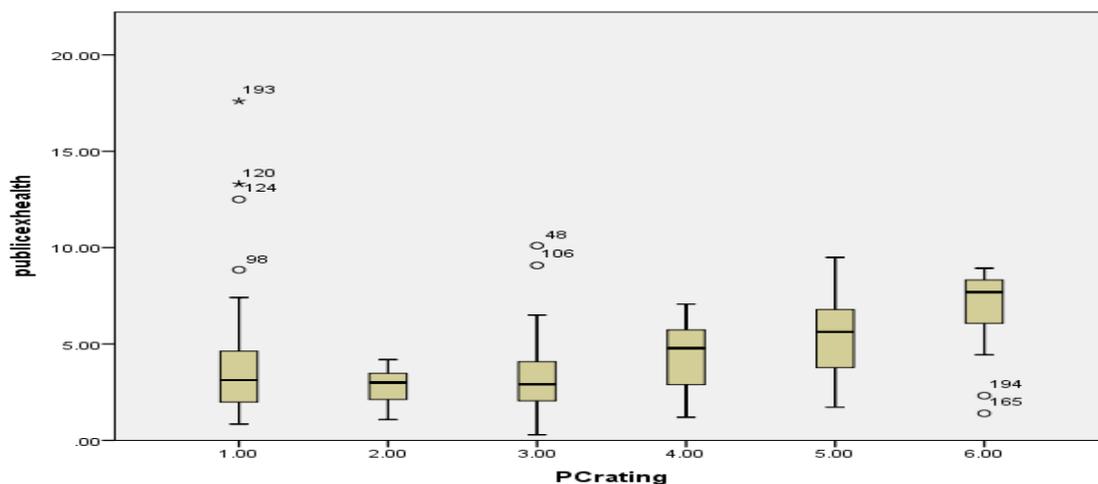
As may be anticipated, consumption of Morphine Equivalent (ME) drugs was associated with higher levels of palliative care development. Consumption of ME drugs has been included within the context of health systems, however, government legislation is necessary in order for the drugs to be available at all. Further, education regarding how to use these drugs is also a necessary component of ensuring access this form of pain relief. What is most notable from international consumption levels of ME drugs, is the degree to which consumption is concentrated in Group 5 and 6 countries and suggests that where ME equivalents are being prescribed and consumed, that they are being used for palliative purposes.

## Political Context

### *Health expenditure, public (% of GDP)*

This variable is a measure of both government expenditure on health, as well as the political commitment to healthcare that this embodies. A moderate positive relationship is displayed by the correlation coefficient between the variables ( $r=0.362$ ). This finding supports the hypothesis that palliative care is better able to flourish and develop in countries where there is strong political backing and financing for provision for healthcare.

**Figure 26: Boxplot examining the relationship between public health expenditure and palliative care development ( $r=0.362$ ,  $p<0.001$ )**



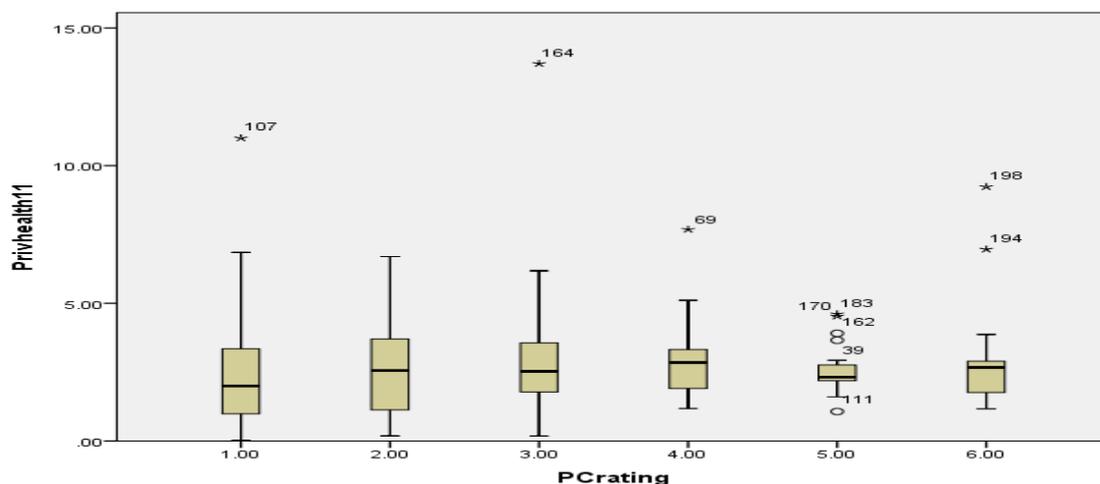
The spread of outliers between the country groups serves as a reminder that there is no natural process from government funding, to palliative care service development. The broadly positive trend

displayed by the boxplot, is however, supportive of the idea that government commitment to publicly funded healthcare provision has served as a fertile context for palliative care services to have emerged [Figure 26].

### **Health expenditure, private (% of GDP)**

This variable is a measure of out-of-pocket spending, private insurance, charitable donations and direct service payments by private corporations. There is a weak positive (non-significant) relationship between private health expenditure and palliative care development ( $r=0.129$ ).

**Figure 27: Boxplot examining the relationship between private health expenditure and palliative care development ( $r=0.129$ ,  $p=0.078$ )**

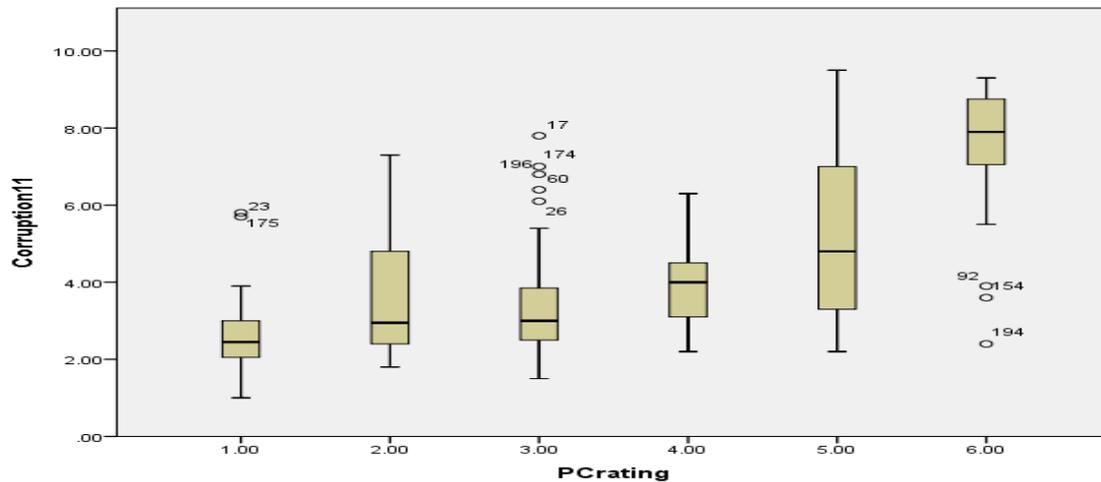


There is, however, no obvious linear trend to the data, suggesting that the indicator has little (if any) general influence over service development [Figure 27]. It is noticeable however that Uganda (194) is shown to have relatively high private expenditure compared with other countries and is a potential line of enquiry for how services have developed in the country.

### **Corruption**

A low Corruption score indicates high levels of perceived corruption. The strong positive relationship ( $r=0.570$ ) between the two variables shows that lower levels of corruption are associated with higher levels of service development [Figure 28].

**Figure 28: Boxplot examining the relationship between levels of corruption and palliative care development ( $r=0.570$ ,  $p<0.001$ )**

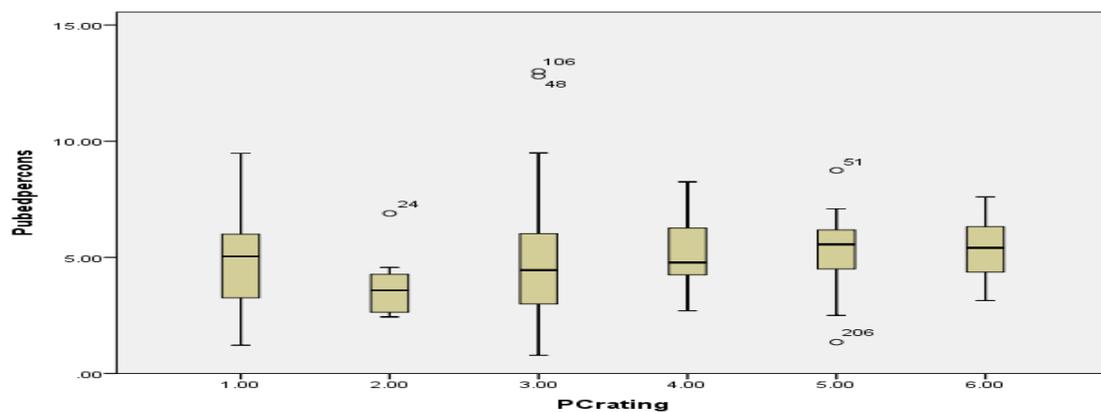


The boxplot does however reveal many outliers. Focussing upon Group 6 (high development) it is shown that palliative care has developed to the highest country group *in spite* of high levels of corruption in three countries (Italy (92), Romania (154) and Uganda (194)).

**Public spending on education, total (% of GDP)**

There is a weak positive relationship between public spending on education and level of palliative care development ( $r=0.182$ ). This finding tentatively supports the rationale for including the indicator, that high government welfare expenditure would be associated with higher levels of palliative care development.

**Figure 29: Boxplot examining the relationship between levels of public spending on education and palliative care development ( $r=0.182$ ,  $p>0.025$ )**



In spite of the positive association, however, the interquartile range of Group 1 countries extends higher than that of Group 6 countries [Figure 29]. Moreover, the median spend of Group 5 Countries

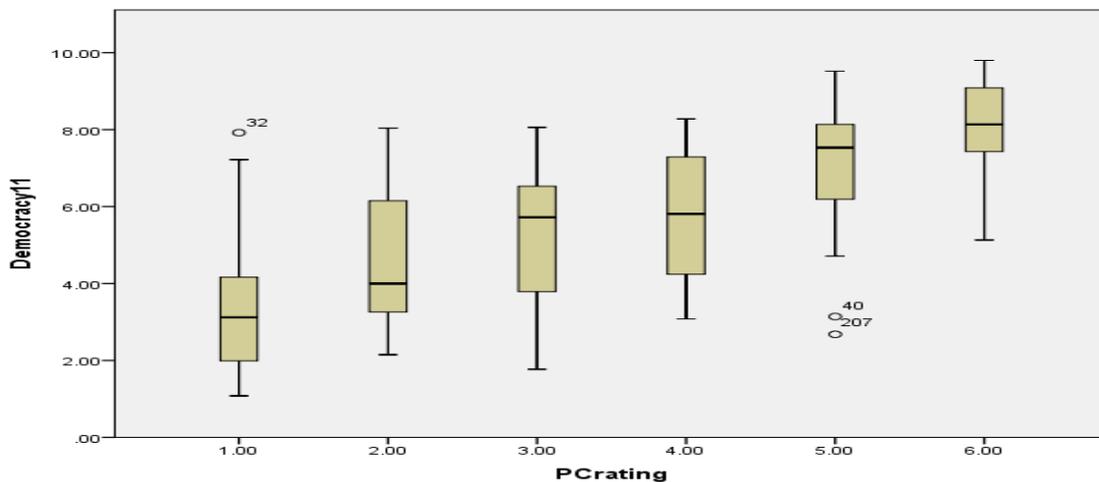
is higher than that of Group 6 countries. Whilst there is no suggestion that decreased expenditure is associated with palliative care development, conclusions suggesting the opposite of this should be treated with caution.

### **Strength of Democracy**

This indicator is a composite score, produced by the Economist Intelligence Unit (EIU), which gives an overall strength of democracy score based on the following elements: electoral process and pluralism, functioning of government, political participation, political culture, and civil liberties.<sup>lxxxvi</sup> For this ordinal variable, a score of 10 indicates ‘perfect democracy’, whilst a score of zero, no democracy at all.

There is a strong relationship between strength of democracy and level of palliative care development ( $r=0.618$ ), which represents the highest correlation coefficient included in the sample.

**Figure 30: Boxplot examining the relationship between strength of democracy and palliative care development ( $r=0.618$ ,  $p<0.001$ )**



There is a clear upward trend relating the strength of countries’ democracy with its level of service development [Figure 30]. In Group 1, Cabo Verde (32) is an outlier, with a relatively strong democracy (7.92), but no known palliative care service at all.

### **Political context and palliative care development**

As may be expected, there is a positive association between public spending on health (% of GDP) and palliative care development, though the relationship is moderate ( $r=0.362$ ). Countries in Group 6

have the highest median public spending on health of 7.69 as a percentage of GDP. This suggests that greater government commitment to health funding may have acted as a facilitator to palliative care development as part of public health approaches.

There was, however, evidence that governments in Group 1 were committing high proportions of available resources to healthcare, but that these resources were not allocated towards palliative care. Moreover, percentage indicators must be viewed within a context of total GNI, whereby a high percentage of limited resources may still represent relatively low levels of financial resources being committed to health. Questions may also be raised by the outliers in Group 1 (n=4), Tuvalu (193), Marshall Islands (120), Micronesia (124) and Kiribati (98)) – where extremely high percentages of GNI were allocated to healthcare. Such countries receive aid from the United States and there is evidence that unusually high proportions of government resources have been allocated towards the private delivery of healthcare which has not benefitted palliative care.<sup>lxxxvii</sup> In Group 3, Cuba (48) and Lesotho (106), have higher than anticipated spending for the group, but have developed only limited capacity for palliative care.

Weaker evidence indicates that higher private spending on health (% of GDP) supports palliative care development. A high amount of outliers across groups suggests that there is little association between level of private healthcare spending and palliative care. Of interest, however, Uganda (194) has relatively high private health expenditure and the relationship between private health expenditure and palliative care in the country may offer one explanation for its high levels of development. Additionally, the inclusion of charitable funding within ‘private funding’ is consistent with a known situation, where much palliative care funding in Uganda comes from charitable funders such as the Elton John Foundation.<sup>lxxxviii</sup> It is no surprise that the United States (198) with its private health system and high levels of palliative care development also appears as an outlier.

Overall, taking public and private expenditure together, there is a clear indication that greater spending on health care, through government and private streams has *some* relationship with palliative care development. There is limited evidence, however, that government commitment to spending on education is having the same effect.

The strength of democracy and levels of corruption within countries had two of the strongest associations with palliative care identified by the analysis. These findings, support theoretical notions that higher corruption leads to poorer health outcomes and that stronger democracies

improve health.<sup>lxxxix</sup> Corruption within governments and at the health-sector level, may lead to decreased access to health services and the misallocation of resources.<sup>xc</sup> Low public awareness and expectation for palliative services may also leave the sector particularly vulnerable to misappropriation of funds. Conversely, the finding that stronger levels of democracy are associated with higher palliative care development supports the idea that stronger political institutions facilitate improved outcomes in terms of universal health policy issues<sup>xci</sup>, including palliative care.

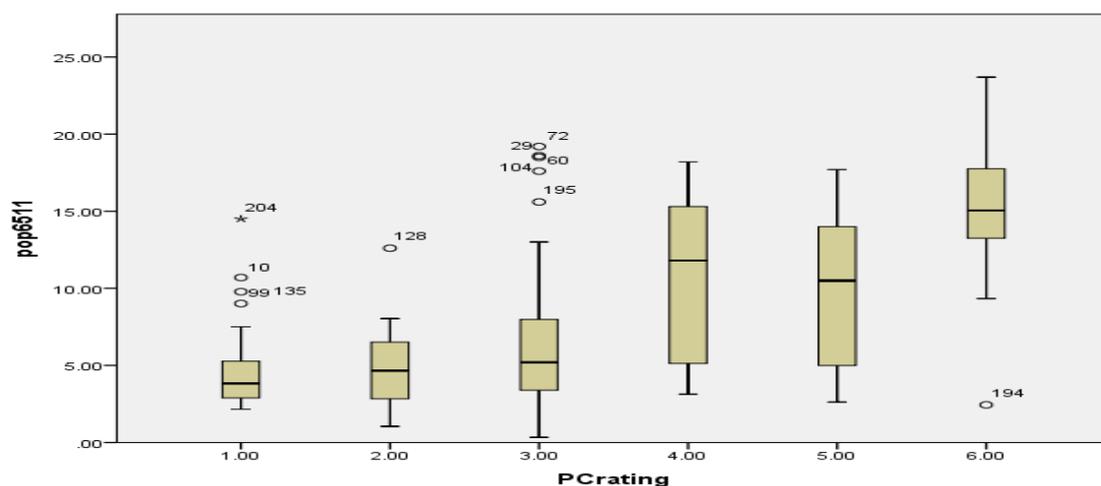
Overall, the findings suggest that political factors may have been able to positively influence the international development of palliative care. This analysis does, however, run both ways. Where indicators of corruption are high and those for democracy and spending on health low, palliative services have developed only to a limited extent or not at all.

## Demographic context

### *Population ages 65 and above (% of total)*

There is a strong positive relationship between the two variables ( $r=0.524$ ). The greater the percentage of people in a country who are over 65 is associated with a higher level of palliative care development [Figure 31]. This supports the hypothesis that palliative care has developed to meet the needs of ageing populations.

**Figure 31: Boxplot examining the relationship between the percentage of population aged 65 and above and palliative care development ( $r=0.524$ ,  $p<0.001$ )**



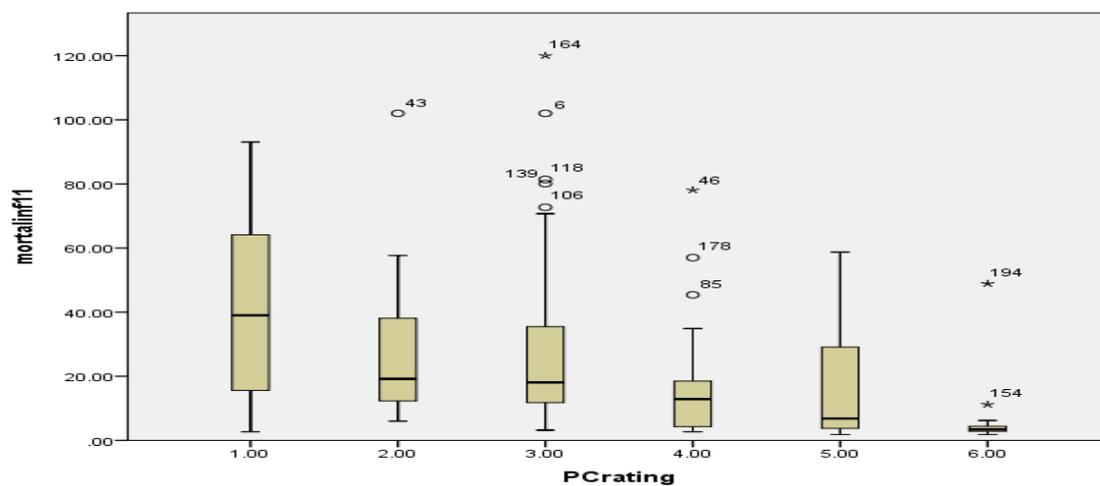
However the boxplot reveals that there are many countries that have high percentages of their population over 65 which have not apparently developed to meet 'the practical needs of an ageing

population'. Uganda is an outlier (194), with a low percentage of its population over 65 and a high palliative care development score.

**Mortality rate, infant (per 1,000 live births)**

There is a moderate negative relationship between the variables ( $r=-0.499$ ) suggesting that infant mortality rates are higher in countries where palliative care is least developed [Figure 32].

**Figure 32: Boxplot examining the relationship between infant mortality rates and palliative care development ( $r=0.499$ ,  $p<0.001$ )**

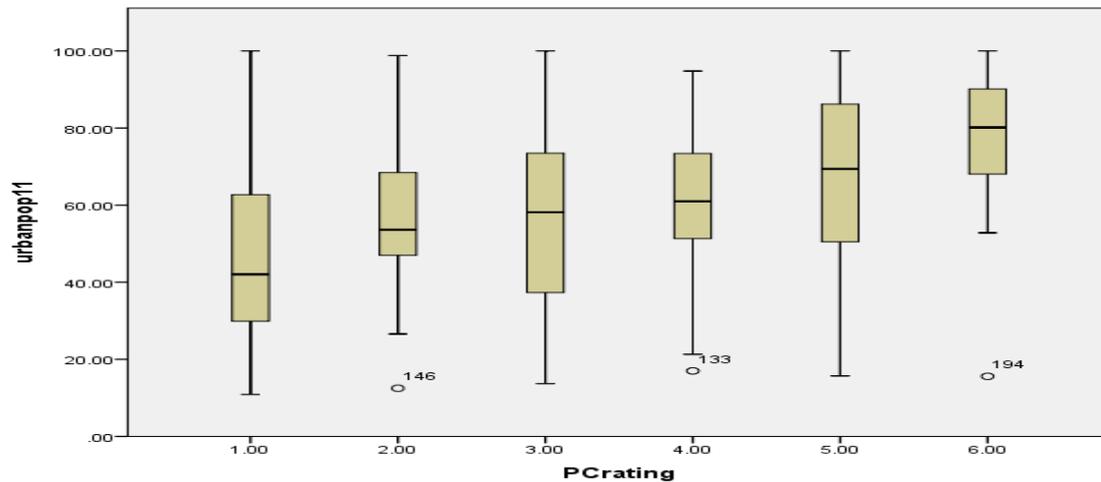


Yet, the high amount of outliers shown in the boxplot, suggest that caution should be exercised before making generalisations about the relationship. Palliative care seems to have developed to a level in certain contexts *in spite* of high mortality rates, however only two Group 6 countries have higher than expected infant mortality rates, Uganda (194), once more, and Romania (154). Overall, the moderate relationship between the variables suggests that countries which have not developed palliative care to a high standard face serious challenges regarding the delivery of other aspects of healthcare.

**Urban population (% of total)**

A moderate positive association ( $r=0.320$ ) links a higher percentage of total population living in urban areas with higher palliative care development [Figure 33].

**Figure 33: Boxplot examining the relationship between urban populations and palliative care development ( $r=0.320$ ,  $p<0.001$ )**



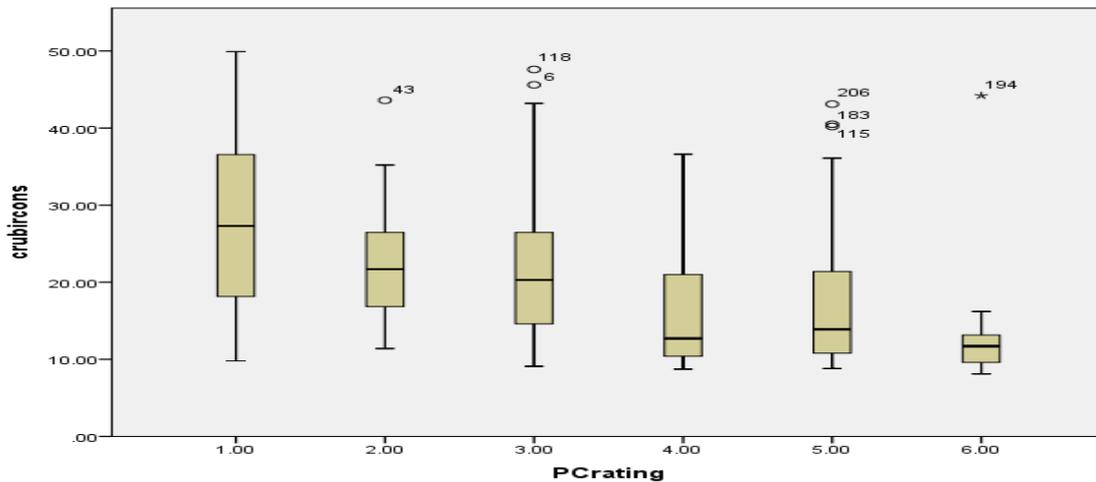
This finding adds support to the suggestion that palliative care services have developed mainly to meet the need of urban populations and that there are additional challenges in providing services in rural areas.<sup>xcii</sup> There are some settings, however, with high proportions of urban populations which have either not developed palliative care (Monaco (135)) or done so to a very limited extent (Qatar (153)). Once more it is difficult to intuitively understand in Monaco there would be no end of life care services at all, whereas Qatar may serve as an example of a country which has not given palliative care any policy attention.

In Group 6, the solitary outlier is once again Uganda (194), suggesting that *either* the country has managed to overcome the challenges of providing services to rural populations *or* that questions must be asked regarding the allocation of the highest level of service development.

***Birth rate, crude (per 1,000 people)***

There is a moderate, negative relationship between crude birth rates and palliative care development ( $r=-0.447$ ) which suggests that in nations where infant mortality rates are higher, that palliative care is less developed.

**Figure 34: Boxplot examining the relationship between birth rates and palliative care development (r=0.447, p<0.001)**

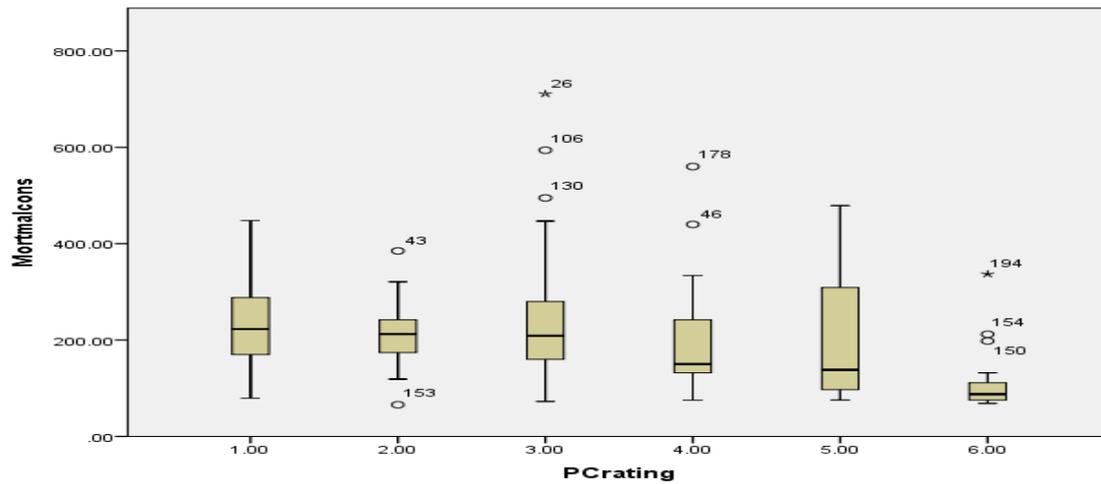


In Group 1 there is a wide range of birth rates, whilst in Group 6, birth rates are characterised by being low [Figure 34]. This finding is in support of the hypothesis that whilst high levels of resources are required to tackle issues regarding birth rates, that need for palliative care has not as yet, been addressed. In Group 6, Uganda (194) is again an outlier, whilst in Group 5, Malawi (115), Tanzania (183) and Zambia (206), have achieved a level of integration of palliative care into their health systems in spite of high birth rates. This suggests that caution should be exercised when considering the relationship between the two variables.

***Mortality rate, adult, male (per 1,000 male adults)***

A moderate negative relationship is revealed between male mortality and palliative care development (r=-0.346) which suggests that male mortality is higher in countries where palliative care is least developed.

**Figure 35: Boxplot examining the relationship between male mortality rates and palliative care development ( $r=0.346$ ,  $p<0.001$ )**

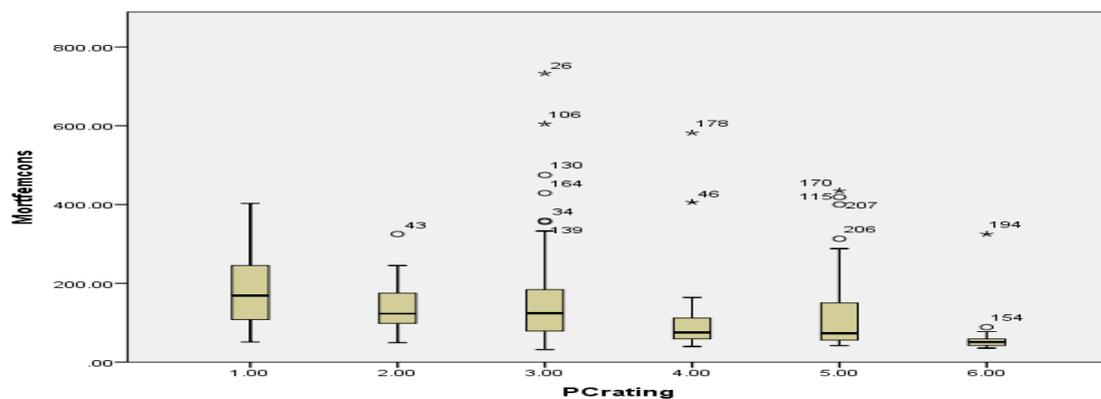


This finding is suggestive that in countries where there is a higher proportion of deaths amongst a population in a given year and the need for palliative care great, that people are unlikely to receive palliative care. The low quartile range in Group 6 indicates that lower mortality rates allow better planning and organization of end of life services [Figure 35]. That said, there is a broad range of mortality rates within Group 5 countries.

***Mortality rate, female, male (per 1,000 female adults)***

There is a moderate negative relationship between female mortality rates and palliative care development ( $r=-0.448$ ), though stronger relationship than that of male mortality rates ( $r=-0.346$ ).

**Figure 36: Boxplot examining the relationship between female mortality rates and palliative care development ( $r=-0.448$ ,  $p<0.001$ )**



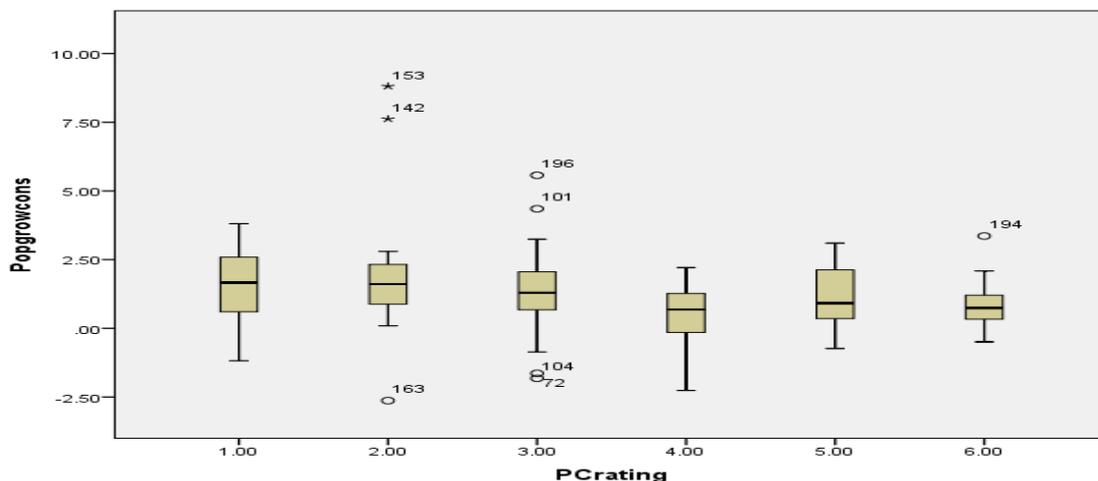
Again, lower mortality rates are concentrated in Group 6 countries – with the exception of two outliers (Romania (154) and Uganda (194)) [Figure 36]. Overall, the indicator suggests that the higher

the risk of dying – and particularly for women - the lower the level of palliative care services that will be available if indeed they are present at all.

### Population growth (annual %)

There is a weak negative relationship between increasing populations and level of palliative care development ( $r=-0.218$ ) which gives a slight indication that palliative care services are less likely to have developed in nations with an increasing population

**Figure 37: Boxplot examining the relationship between population growth and palliative care development ( $r=-0.218$ ,  $p<0.002$ )**



The boxplot indicates, however, that conclusions should be drawn regarding this relationship with caution as there appears to be no clear trend to the relationship [Figure 37].

### Demographic context and palliative care development

The WPCA study reports that palliative care services have developed to meet the needs of ageing populations. This argument is supported, as countries which have a higher percentage of people over 65 in the population, tend to have achieved higher levels of palliative care development. Using this indicator does, however, overlook the fact that many people die under the age of 65 who may benefit from palliative care.

In countries where people are more likely to die within a given year, based on mortality rates, palliative services are less likely to have developed. In countries where birth rates continue to outnumber death rates (increasing populations), services are also less likely to have developed.

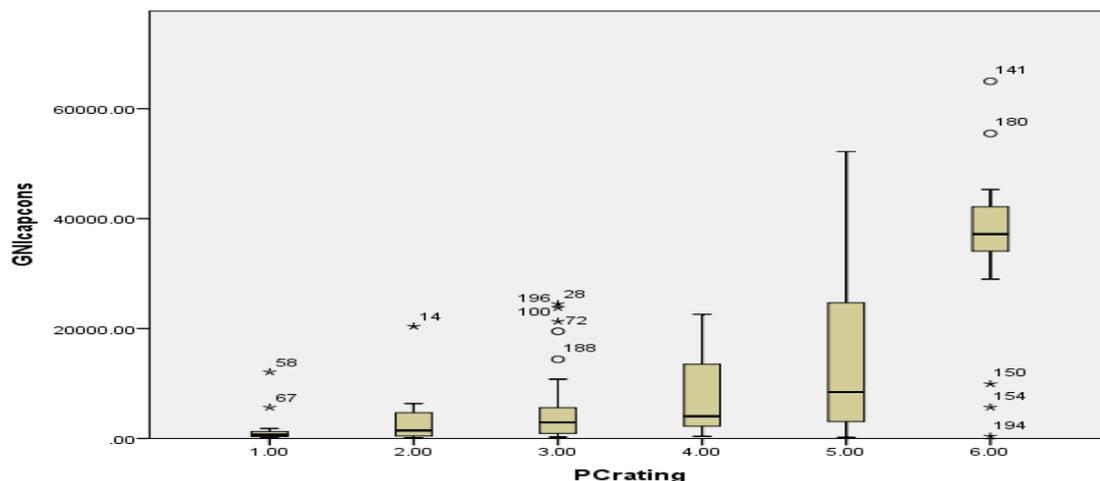
Evidence also emerges that there is inequity within countries regarding access to services. Countries with a higher percentage of their population living in urban areas are more likely to have developed palliative care, which suggests that people living in urban areas are more likely to have access to services. This finding mirrors those of a study within the systematic review which describes additional challenges regarding providing services to rural populations.<sup>xcii</sup>

## Economic Context

### *GNI per capita (constant 2005 US\$)*

A strong positive relationship exists between GNI per capita and level of palliative care development ( $r=0.595$ ) which suggests that richer nations are more likely to have developed services than poorer countries. A positive upwards trend is displayed by the boxplot before a leap in GNI amongst Group 6 countries [Figure 38].

**Figure 38: Boxplot examining the relationship between GNI per capita and palliative care development ( $r=0.595$ ,  $p<0.001$ )**

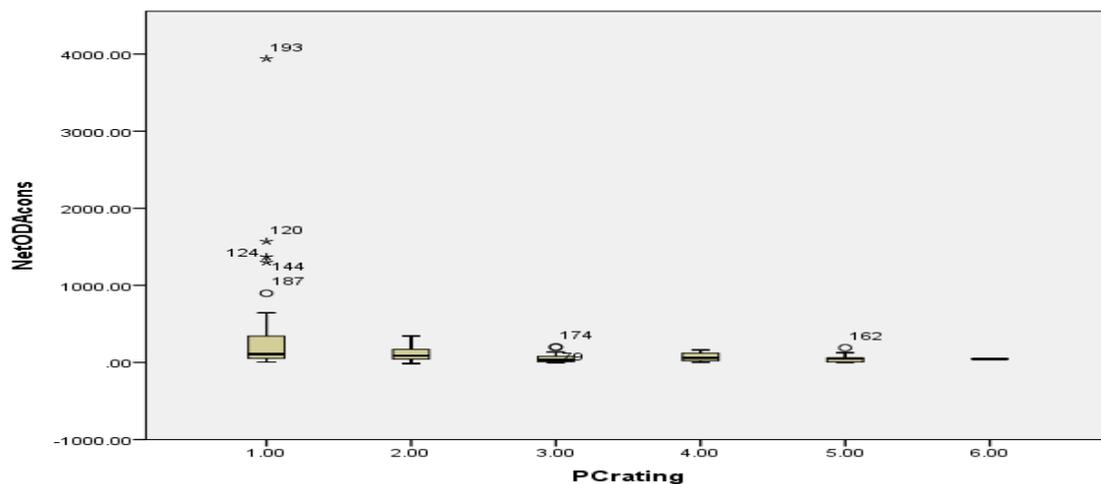


There is evidence that some countries with high GNI have made little progress in developing palliative care. Equatorial Guinea (58) is an outlier amongst Group 1 countries, whilst the Bahamas in Group 2(14) has only capacity building initiatives despite a per capita GNI of >\$20,000 per capita. Of note also, three Group 6 countries (Poland (150), Romania (154), Uganda (194)) have achieved the highest level of service development in spite of a GNI per capita far below what may have been expected. This supports the suggestion that a nations' wealth is not the sole determinant of palliative care development.

### Net Overseas Development Assistance (ODA) received per capita (current US\$)

A moderate, negative relationship is revealed by the correlation coefficient ( $r=-0.376$ ). Net receivers of ODA are concentrated amongst Group 1 and 2 countries [Figure 39]. In Group 5, Serbia (162) - a relatively new independent nation following military conflict - appears as an outlier.

**Figure 39: Boxplot examining the relationship between ODA per capita and palliative care development ( $r=-0.376$ ,  $p<0.001$ )**



The relationship supports the idea that net donors of aid have also been able to better develop palliative care services. It also suggests that development aid is not being (or has not yet been) used to support the development of palliative care.

### Economic context and palliative care development

Using Gross National Income (GNI) per capita as a measure of a country's wealth, there is clear evidence that richer countries are more likely to have developed palliative care services than poorer countries. In line with this, it makes rational sense, that wealthier countries are net *donors* of Official Development Assistance (ODA) whilst poorer countries receive this money. There is not, however, any evidence that net receivers of ODA have used these financial flows to forward palliative care development when viewed globally. Countries which receive ODA are less likely to have developed palliative care services, which supports the broader finding that palliative care has not yet engaged successfully with global funding agencies.

## Discussion

The findings of this Chapter both support and challenge the notion of transferability of palliative care policies and practices. It has been shown that countries such as the United Kingdom (197) and Australia (11) which have successfully integrated palliative care into their health systems have similarities *beyond* simply indicators of wealth and high life expectancies. Conversely, in lower-resource settings it has been shown that failure to develop palliative care services is one developmental challenge which sits alongside many others.

### Transferability of services

Understanding palliative care development in terms of broader development context and similarities, moves the discussion on from explaining policy diffusion in terms of 'geographic clustering', where policy convergence is explained in terms of a natural spread of good ideas and practices.<sup>iii</sup> The general convergence of geographic clusters towards integration into health systems seen most clearly in Europe and North America, is thus better understood in terms of the contextual similarities between the countries.<sup>xciii</sup> That is, it appears that structural similarity of nations rather than geographic proximity is the clearest explanation of palliative care practices have converged between countries. This analysis also helps us to explain why other 'similar' countries in terms of these contextual factors have developed palliative services similarly in spite of geographic distance. Australia's presence in Group 6 may be explained in this manner as a literal 'island of development' in a continent characterised by low provision of palliative care [Figure 10]. Furthermore, there is evidence that palliative care has developed to the highest level in countries with strong democracies.

Additionally, 'broader support networks' in the form of the WHO and bilateral donations from Italy to strengthen home based care have contributed to Uganda's apparent success in rolling out services.<sup>xciv</sup> However, given the questions which were raised with regards to the validity of Uganda's ranking as a Group 6 country, based upon its relatively low score within the EIU Quality of Death index, some questions are raised.<sup>xvii</sup> Owing to Uganda's consistent presence as an outlier within correlations, it may be asked whether the country has achieved success *in spite* of broader contextual factors, or whether it's rating as a Group 6 country is appropriate.

Contextual similarity does not solely drive policy convergence. Indeed there are other dynamic processes at work in Sub-Saharan Africa which have led to a cluster of Group 5 and 6 countries in the

region [Figure 3]. Hospice Uganda was established, following the inauguration of Africa's first Hospice in Zimbabwe in 1990, with the mission statement of becoming "a 'model' hospice which would be affordable and culturally acceptable to Africa and could be adapted to the different circumstances".<sup>xcv</sup> Characterising hospice in Uganda as a model for Sub-Saharan Africa, contains the implicit suggestion, that countries in the region have *similarities*, or shared characteristics which may make similar policies both feasible and amenable. Supported by Hospice Africa, an Organization established to promote the spread of the practice of palliative care through educational efforts, there is already suggestive evidence of policy diffusion emanating from Uganda. That Hospice Uganda itself was only founded in 1994, adds a more optimistic outlook on the development of palliative care in Sub-Saharan Africa which appears to be occurring with some dynamism.

Based upon the findings of the chapter, it may be fruitful for national policymakers seeking to implement the terms of the WHA palliative care resolution to look not just at neighbouring countries, but at other countries of similar developmental level in order to learn lessons regarding how palliative care can be implemented. For instance, due to its success, the 'Kerala Model' has received attention from policymakers from countries as diverse as Thailand, Ireland and the Seychelles.<sup>xcvi</sup> Of course there may be lessons to be learned from what has been achieved in Kerala, for instance the benefits of community-engagement in provision of services. However, policymakers seeking to *transfer* the model must consider a broad range of contextual factors. For instance, beyond considerations of social indicators, Kerala is the third most densely populated state in India<sup>xcvii</sup>, has this made it easier to foster community participation?

Moreover, as part of volunteer-training in Kerala, potential volunteers are asked to understand concepts such as the basics of cancer care, effective communication, complete assignments and projects, tasks which appear reliant upon a good level of education.<sup>xcviii</sup> Additionally, from a history of political socialism, democracy is said to 'work better' in Kerala, which is consistent with the finding that palliative care develops most strongly within robust democratic systems.<sup>xcix</sup> In this regard, other Indian states may be regarded as *dissimilar* to Kerala in many respects in spite of geographical proximity. Further analysis is needed in order to determine which other regions or countries may be considered 'similar' to Kerala. In this regard, it is perhaps telling that no other state in India has as yet adopted the 'Kerala model.' However, there are currently efforts to implement the Keralan model in West Bengal - another state in India.<sup>c</sup> It will be interesting to discover whether this policy transfer is successful, though unfortunately there is no evidence currently in the public domain to make judgement.

## Need for model services

The findings of this chapter further commend the achievements of ‘model services’ which have developed in contexts of low development indicators. Significantly model services appear to have driven processes of policy convergence more easily in geographic regions of contextual similarity. For instance, in Sub-Saharan Africa, palliative care appears to have spread rapidly between similar countries, in spite of relatively low socioeconomic and health indicators. In this regard, we may attribute much of the success in rolling out palliative care to the qualitative factors such as ‘increased awareness of policymakers’ identified by the WPCA study.<sup>ii</sup> Certainly the work of Anne Merriman, Hospice Uganda’s founder can be described as that of a ‘palliative care champion’. Additionally, ‘focussed advocacy’ has been offered as a reason for the early adoption of palliative care by Uganda’s Ministry of Health, which has facilitated access to opioids and seen palliative care incorporated into the National Health Policy Plan.

Of concern for the continent, however, is that the ‘cluster of higher development around Uganda does not yet seem to have made an impact in the rest of Africa. This may be explained due to the disproportionately high level of global attention focussed upon Sub-Saharan Africa during the MDG era which has seen high levels of finance and technical assistance targeted upon the region.<sup>ci</sup> There are also clear contextual dissimilarities between Northern and Southern Africa, in terms of race, climate and language.<sup>cii</sup> It was not feasible to investigate such factors within this study, but they may form some explanation for why ‘lessons’ emanating from Uganda are less receptively learned in Northern countries. In this regard, it may be said that new ‘model services’ are needed which are appropriate for distinct regions such as Northern Africa.

Elsewhere, in other regions of low provision – such as Latin America and the Caribbean - attention should be given to identifying and facilitating ‘model services as well as potential contextual similarities between countries. In 2002, seven ‘demonstration projects’ in 7 countries (Argentina, Barbados, Chile, Colombia, Ecuador, Panama, Venezuela) were awarded funding by the Pan American Health Organization (PAHO) to expand palliative care services.<sup>ciii</sup> From this grouping, Chile has achieved Group 5 status (preliminary integration into the health system) along with Puerto Rico and Costa Rica, a country which incorporates palliative care as part of universal health coverage.<sup>civ</sup> Additionally, the Chilean government has mandated that health centers are required by law to require high quality care, with palliative care a part of this.<sup>cv</sup>

Focussed attention should be given to how these policies and ‘model services’ have achieved success, and the structural contexts in which they have developed. Concerns must, therefore, be raised, regarding the levels of international research activity focussed upon the region, with only 23 studies identified in Chapter Five which focus upon Latin America and the Caribbean. This suggests, that researchers are not yet fully utilising the potential of research and evaluation, to facilitate processes of ‘lesson learning’ and policy diffusion in the region.

### **Low palliative care development consistent with nations facing broader development challenges**

This chapter has revealed the scale of the challenge facing governments who have ratified the WHA Resolution but have not yet developed palliative care. In spite of the achievements of model services, which suggest that palliative care is feasible in all world contexts, the frequency with which examples such as Kerala and Uganda are used underlines their rarity. In this regard, focussing upon positive examples undermines the challenges which exist for the further development of palliative care. In countries which haven’t developed palliative care, based upon the findings of this chapter, life expectancies and government spending on health are likely to be low. The greater narrative therefore is that palliative care is one among many other developmental challenges faced by nations. Moreover, whilst awareness of palliative care amongst public and policymakers remains low<sup>cv</sup>, there is little to suggest that its development will be prioritised over and above other prevalent areas of social need.

Although there is evidence that palliative care is something which is introduced as other development indicators increase, the scale of other issues which require attention in such nations suggests that if palliative care development is to be accelerated in such circumstances, that new approaches are needed.

## **Conclusion**

This chapter has demonstrated that there are strong links between level of palliative care development and other structural indicators of development. It has been shown, that palliative care has developed most fruitfully in nations which have strong development indicators relating to six structural domains; health systems, socioeconomics, disease-demographics, population demographics, politics and economics. Alongside the qualitative factors identified by the WPCA study, it seems that there is some natural development of palliative care services along with other

indicators of country development. That is, that palliative care seems to come along with broader development improvements within a country. However, such processes do appear to become accelerated when 'model services' are able to act as policy genera and promoters of education.

There is evidence to suggest that palliative care has developed similarly, in similar national contexts. Socioeconomically similar countries in Western Europe, North America (as well as Australia) have all achieved the 'highest' levels of palliative care development, from contexts of other strong development indicators. Additionally, examples from Sub-Saharan Africa show that some countries have been able to develop palliative services *in spite* of national contexts of low development and there is an apparent regional cluster emerging around Uganda.

However, in spite of this global development which has seen palliative care develop in all regions of the world, it is important not to underestimate the challenges which still remain in all settings. Whilst the WPCA rankings are useful in order to survey the international picture, even in settings which have achieved integration of palliative into the broader health system, such as the United Kingdom, services are not yet available to everybody who would benefit and there are further questions relating to quality of care.<sup>cvi</sup> Elsewhere, services remain either patchy or non-existent within developmental health systems which struggle to provide even a basic standard of healthcare services. In this regard palliative care activists must acknowledge that that the adoption of a public health approach to palliative care development, which incorporates calls for a reallocation of existing resources, means that such resources would have to be taken from other areas of social need.

Whilst the ongoing spread of palliative care practices appear to have a developmental momentum, without further intervention, millions of people will continue to suffer due to lack of access to high quality pain and palliative services. Although facing different challenges, what unites all world regions in terms of palliative care, is that they would all benefit from greater attention from policymakers and investment in services. In this regard, in order to accelerate palliative care development *beyond* that which appears to occur alongside other processes of countries' development, it is clear that more must be done in order to attract greater engagement from such stakeholders at all levels of governance.

In Chapter Three theoretical understandings of policymaking processes were offered in terms of how certain health issues have become prioritised over and above other worth claims through strategic

and targeted advocacy. Accordingly, the following chapter presents a thematic analysis of the views of key experts in the field of international palliative regarding current advocacy efforts and how global advocacy for palliative care may become more refined.

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## Chapter Seven

### Can palliative care development be furthered through global advocacy?

#### Introduction

In the previous chapter [Chapter Six], it was shown how palliative care development has been highly consistent with the broader development level of nations. This is significant for two reasons. Firstly, the scale of the broader development challenge faced by many nations, which have not yet developed palliative care to a high level in terms of low life expectancies, poor maternal mortality rates and so on, is large. Secondly, the achievements of ‘model services’ such as Hospice Uganda are underlined, in that they appear to have emerged *in spite* of this broader context of relatively low levels of development. In this regard, two key reasons for the establishment of the Palliative Care Association of Uganda and the Association of Palliative Care in Africa have been identified as financial support from international charitable organizations as well as targeted advocacy of the national government by Hospice Uganda.<sup>1</sup>

In many senses, this scenario reflects the broader development challenges to palliative care. That is, the need to raise the awareness of policymakers as well as attract new sources of finance to fund the development of services. In this regard, in Chapter Three it was suggested that palliative care has not yet received attention from global health actors who have the resources and influence to accelerate the development of palliative care. One suggested reason for this lack of engagement of global actors was that activists had not yet ‘framed’ palliative care in ways likely to attract the attention of global funding agencies.

Yet, Chapter Six showed that palliative care development appears to have some natural momentum and that the pace of this is highly consistent with other developmental progress within nations. This raises the question: how the current pace of palliative care development may be accelerated through global advocacy efforts? It is to this topic that this chapter now turns.

#### Rationale for the study

As global attention moves towards the incoming Sustainable Development Goals (SDGs), there is a real opportunity for palliative care to make gains as part of moves towards the attainment of

Universal Health Coverage (UHC).<sup>ii</sup> However, the absence of an indicator to measure progress towards the implementation of the 2014 World Health Assembly (WHA) Resolution for palliative care is of concern. Furthermore, that palliative care sits alongside more measurable SDGs for instance reduced maternal mortality<sup>iii</sup>, suggests that it will not receive prioritisation in comparison to other such issues. In this regard, ongoing low awareness of palliative care amongst global health actors<sup>iv</sup> and the absence of an indicator with which to measure progress risks a scenario where palliative care may not be identified as an important element of UHC – in spite of the WHA Resolution.

It was established in Chapter Three that global policymakers do not necessarily prioritise issues based solely upon need, but also upon how social problems are ‘framed’. Until now, palliative care has most commonly been framed as a human rights issue, through proclamations such as the Prague Charter, which called for governments to acknowledge palliative care as a human right.<sup>v</sup> However, it has been noted that not all frames hold the same likelihood of influencing policymakers.<sup>vi</sup> Moreover, it has been identified that human rights frames may not be useful in terms of engaging global health funders such as the World Bank, who conceptualise health economically, as an issue of human capital.<sup>vii</sup> In this regard, this current chapter considers the views of experts regarding how the argument that palliative care is a human right is constructed as well as questions regarding its potential to achieve policy gains. Moreover, in recognition that social issues can be framed in multiple ways, alternative ways of ‘framing’ palliative care are considered in terms of their relative potential to influence policymakers.<sup>vi</sup>

Yet, how issues are framed is not the sole determinant of whether certain issues receive prioritisation. Aspects of a successful advocacy strategy are commonly said to hinge around two key rhetorical steps: firstly, establishment of a ‘problem’ as severe and neglected, as well as to present a ‘solution’ regarding the tractability of the problem and the benefits which would accrue from addressing it.<sup>lxv</sup>

In this regard, this chapter raises concerns regarding the clarity with which palliative care is presenting these rhetorical steps. Chapter Two identified how the need for palliative care is often presented using disease statistics, an approach which is undermined to some extent due to low levels of understanding of what palliative care *is* as well as competing understandings of its meaning. Additionally, given the relatively low grade of studies identified in Chapter Five with which advocates are able to present the ‘solvability’ of the problem of lack of palliative care, it is appropriate to

consider expert views regarding *why* a lack of palliative care is a problem, how palliative care addresses the problem and what the benefits are of increased access to it.

This chapter emerged to answer such questions. Sixteen key international palliative care experts were recruited with a view to consider how global palliative care advocacy efforts may be refined in order to engage with new global actors, attract new sources of funding and ensure that palliative care makes gains within the global health priority of achieving UHC. Thus contributing towards answering the overall research question of this thesis:

*Can the global development of palliative care be furthered through increased understanding of global policymaking processes and the presentation of palliative care as an international development issue?*

The study aimed to meet the following aim and objectives:

#### **Key aim**

- To explore the views and perspectives of international palliative care experts regarding existing and future advocacy strategies

#### **Objectives**

- Refine how the problem of lack of palliative care is defined
- To consider what the 'key asks' of the palliative care community are
- Identify key targets for advocacy and consider how palliative care should be 'framed' to appeal to different actors at global level
- To identify key challenges to the further development of the field
- Consider the relationships between existing and potential 'allies' for the palliative care lobby
- To examine existing international advocacy strategy for palliative care in relation to World Health Organization guidance on the key tenets of a successful advocacy strategy

## **Approach and methods**

### **Design**

Explorative qualitative interviews with key experts were conducted as an appropriate strategy to improve understanding of how the problem of lack of palliative care services is structured.<sup>viii</sup> This approach is in line with the objectives of the study to consider how arguments for increased palliative care availability internationally can become more refined. Moreover, it is consistent with the broadly interpretivist standpoint undertaken during the study and the objective of the chapter to increase understanding, rather than generate any objective ‘facts’.<sup>ix</sup>

### **Study population sample and consent procedure**

Semi-structured, in-depth interviews were conducted with a sample of 16 key experts with diverse backgrounds. Experts in the field of international palliative care were recruited for their ‘epistemic expertise’, meaning their capacity to provide strong justifications for a range of propositions within the subject.<sup>x</sup> As the study has a global focus, the sample participants were recruited from all regions of the world including: low-, middle- and high-income countries. As palliative care is a multidisciplinary field, participants were included from varied areas of specialty, but they were united by being leaders within the field and consisted of people holding influential positions within the field.<sup>xi</sup> . Although all participants had an international presence, their ‘region’ was based upon their country of origin. However, the focus of their work and their previous experiences emerged during interview and was noted. Participants were not directly asked for their ethnicity, nor for their nationality, in order to reduce the extent of identifiable information collected and thus to assist with maintaining their anonymity.<sup>xii</sup>

Additionally, in order to balance technocratic opinions against the views of the public, one public-patient representative who had experience in palliative care research was included in the sample. This inclusion is in line with guidance that healthcare research “needs patient input at every level if it is to succeed [2015]”.<sup>xiii</sup>

Purposive sampling was initially used in order to ensure that participants would have high levels of understanding and insight into the research questions.<sup>xiv</sup> This approach was also used to ensure that

there was representation of all habitable world regions within the study. Prior to the commencement of recruitment, it was considered that 10-15 participants would be included within the sample. This figure was determined as it was deemed to be both feasible in terms of recruitment and also, given the nature of the study population of key experts, sufficient to provide a rich dataset reflecting differing views and experiences.<sup>xv</sup> Nevertheless, the sample size of 10-15 remained under constant review.

Using a purposive approach, key experts in international palliative care were identified based upon talks attended at international conferences as well as accumulated knowledge of the field. Potential participants were approached via e-mail inviting them to participate in the study. For instance, the first participant recruited to the study in this manner was approached as they were known to be a senior pharmacist working to increase access to palliative care essential medicines within an international Organization. A Participant Information Sheet (PIS) [Appendix 7] was attached, which described the project and the nature of their potential involvement. A copy of the Consent Form [Appendix 8] was also sent which showed exactly what they were being asked to consent to. In some instances, the Interview Guide was also provided Table 16. Potential participants were encouraged to ask any questions they may prior to their involvement in the study in line with Good Clinical Practice (GCP).<sup>xvii</sup>

Originally, the intention was to take Informed Consent either electronically or in writing. However, following feedback from the Research Ethics Committee (REC) it was decided that this may create an unnecessary barrier to study recruitment due to practical complications taking written consent electronically.<sup>xvi</sup> On this basis and as potential participants were not considered to be part of a 'vulnerable population', audio-recorded oral consent was considered to represent full Informed Consent.<sup>xvii</sup> Nevertheless, all points of the Consent Form were read aloud to study participants and consent taken prior to the commencement of interviews.

As potential participants were professional people and the study is low risk, there was no formal 'cooling off' period, an approach approved by the REC. Therefore, if participants read the PIS and were happy to participate, then consent was taken immediately and an interview arranged or commenced. Potential participants were left to consider their potential participation for as long as they needed and the date and time of interviews was designated by participants. Moreover, it was made clear to participants that they were free to end their interview and withdraw from the study at any time.<sup>xviii</sup>

Having identified several participants and conducted one interview, in order to supplement recruitment a 'snowball approach' to sampling was adopted.<sup>xix</sup> This involved asking study participants both in the PIS and during interview, to recommend other suitable potential participants anonymously. Most prominently, this process took place at the European Association for Palliative Care (EAPC) Conference in Copenhagen in 2015. Several interviews (n=7) were conducted at the Conference where the study generated a good deal of interest. Participants recruited in this manner were also provided with the PIS and Consent Form before informed consent was taken orally prior to the commencement of interviews.

It is acknowledged that the adoption of a 'snowball' approach to sampling carried with it risks of 'community bias', whereby, experts would recommend further participants in their sphere of interest only.<sup>xix</sup> However, as to some extent, it was the relatively small international palliative care community which recruitment aimed to identify, this approach was deemed justifiable. Moreover, as a purposive approach was also maintained, diversity within the sample was achieved.

For instance, using this approach, Africa emerged as a region of specific interest, due to the diverse range of ethnicities and socioeconomics within the region. Two interviews with participants from Africa, both of whom hailed from a richer nation and were not ethnically 'African'. Therefore, it was deemed appropriate to include an additional participant from a different socioeconomic setting within Africa (Kenya) who brought a different perspective to the study.

The interview-process was never intended to be a consensus-building exercise and instead was explorative, aiming to explore how key issues and problems are structured<sup>viii</sup> in relation to how the field of palliative care should move forwards. On this basis, after sixteen interviews had been completed, it was decided that based upon the richness of the data which had already emerged alongside considerations of feasibility that recruitment should close. A brief overview of the characteristics of the study population is presented in Table 15 along with the length of each interview. Although detail is kept to a minimum in order to protect participants' anonymity, it should be made clear that the sample included significant actors in international palliative care. Such involvement may be summarised as working with and between a diverse range of International Organizations, International Associations of palliative care as well as actors working across a diverse range of countries internationally.

**Table 15: Characteristics of study population (n=16)**

<b>ID</b>	<b>Area represented</b>	<b>Primary training</b>	<b>Illustrative international role(s) and expertise</b>	<b>Interview length</b>
01	Europe	Pharmacist	Senior Pharmacist for International Organization	00:52:33
02	N. America	Activist	Advocacy Officer for International Palliative Care Association	00:30:37
03	N. America	Physician	Consultancy for International Palliative Care Associations	00:28:50
04	Asia	Physician	President of National Association of Palliative Care International palliative care education coordinator	00:31:05
05	Asia	Physician	Medical Director of National Hospice Consultancy for International Palliative Care Associations	00:44:40
06	Africa	Paediatric Nurse	Chief Executive of an International Children's Palliative Care Association	00:29:50
07	Africa	Physician	CEO of national Hospice Palliative Care Association Chair of International Palliative Care Association Technical advisor to International Organization Director of global palliative care media outlet	00:42:46
08	Europe	Project Manager	Project Manager of philanthropy organization funding European palliative care leadership training	00:26:33
09	S. America	Physician	Executive Director of International Hospice Association	00:46:28
10	Europe	Private Physician	EAPC Task Force Member of Regional Palliative Care Association International Researcher Pharmaceutical Consultancy	00:58:15
11	Europe	Patient-Public Representative (PPI)	Experienced PPI Representative	00:37:35
12	N. America	Human Rights Activist	Associate Director of Health and Human Rights Organization	
13	N. America	Physician	Board Member International Palliative Care Association	00:54:29
14	Australasia	Physician, Lawyer	International Human Rights Law International palliative care capacity building consultant	01:12:23
15	S. America	Physician	President of Regional Palliative Care Association	Written response
16	Africa	Activist	Co-founder of Regional Palliative Care Association Implementation and evaluation of palliative care services across Africa Lobbyist and Advocacy Officer for International Philanthropy organization	01:07:02

It should be acknowledged, that due to the global focus of the project, it was not feasible to use a sample which could be said to 'representative' of all global expert views on palliative care. Additionally, it is not reasonable to suggest that any given participant could speak for all issues of relevance to a specific region. Thus, it is not appropriate to say that 'data saturation' was achieved although this was never an aim of the study. However, recruitment was ended when it became clear that significant issues began to continually recur.<sup>xx</sup> For instance, no new perspectives were emerging with regards to the suggestion that access to palliative care should be considered a human right. Instead, different viewpoints which had already emerged during interviews were being either interpreted slightly differently or reinforced. Practical realities also dictated that additional recruitment would risk the feasibility of the delivery of the project.<sup>xx</sup> Moreover, within the relatively small field of international palliative care, availability of suitable professionals was a present issue. However, it should be noted that the inclusion of 16 key experts goes over and above guidance which suggests that it is "sometimes difficult to think of more than ten interviews [Saumer and Given. 2013.p.25.]".<sup>xx</sup>

### **Interview procedure**

All interviews (n=16) were conducted by JC between 04/05/2015 and 10/07/2015. Eight out of sixteen interviews were conducted face-to-face, seven of which at the EAPC Congress in Copenhagen and one in Sheffield. Seven interviews were conducted via skype. All interviews were recorded using a 'Zoom H1 Handy Recorder'. Recordings of all interviews came out clearly and did not present difficulties for the transcriber (JC). Due to language difficulties, one participant responded to the questions in writing with follow up questions by the author sent and responded to via e-mail. Semi-structured interviews were conducted using a pre-developed Interview Guide [Table 16]. The Guide was piloted with an international palliative care researcher (LB) who was not part of the final sample.

This useful exercise did not change the substance of questions but led to them being expressed in a more meaningful way.<sup>xxi</sup> After refinement, this guide formed the basis for all interviews [Table 16]. As the interview process progressed, questions became increasingly 'off-script' in order to both gain data on key areas of interest which had not been covered in other interviews as well as in response to emerging areas of interest. Thus, to some extent, the responses of earlier participants who ascribed diverse meanings to the same question, informed further questions for later interviewees. This approach was justified, as neither the questions nor analysis required quantifiable data.<sup>xi</sup>

Moreover, the intention of qualitative interviews was largely to facilitate rich conversation, rather than gain stock responses to rigid questions.<sup>xxii</sup>

**Table 16: Interview guide provided to participants**

Could you please describe briefly how your work relates to palliative care in an international context?

It is often said that there is a global need for palliative care. What do you think is meant by this?

Are there examples from around the world where palliative care is working well and what are the benefits (and for whom)?

Who are the key organizations/individuals/partners involved with palliative care advocacy at global level who are best positioned to influence decision-makers?

How is the current argument promoting palliative care being made at global level?

How does palliative care fit in with current global health priorities? Do current policies help or restrict further development of palliative care?

What do you think should be the overall objective for global palliative care advocacy?

What do you think should be the key message which palliative care advocates should deliver to decision-makers?

What, in the short term, what would be three realistic changes that you would like to see at global level that advocates should focus on?

Who are the key decision-makers/global organizations that palliative care advocacy should seek to influence?

Who are potential key partners for the palliative care lobby that do not work in palliative care currently?

Different arguments for palliative care may resonate with different global actors. Can an argument be made for palliative care within the following domains?

- International Development (as an economic issue)
- As a Human Rights Issue
- As an issue for the private health care actors
- As an ethical or moral imperative

What are potential barriers/arguments against the further roll-out of palliative care?

Case notes and observations were recorded both during the interviews as well as immediately after, to identify emerging areas of interest, additional questions for future participants and to assist with analysis in line with good interviewing practice.<sup>xxiii</sup>

## **Data Management**

Interviews were stored on an encrypted laptop and transcribed within one week of the interview date. Each participant was assigned a unique Study ID in to retain their anonymity on transcripts. Identifiable data including e-mail correspondence and a sheet which links each participant's name and their Study ID were stored on an encrypted device separate to that which non-identifiable study data was stored. During transcription, any names of individuals which were given during interview, were replaced by 'XX' within transcripts. Names of organizations given during transcription were recorded due to their relevance the study. However, no participant job titles which may have made individuals identifiable through their association with organizations were reported.

Transcripts (n=16) were imported into 'NVivo 10 - Qualitative Data Analysis Software' for analysis.

## **Thematic analysis**

Thematic analysis took place within five distinct stages:

1. Sensitisation to the data
2. Free coding
3. Theme development
4. Review of themes
5. Iterative approach to writing

### **Step one: sensitisation to the data**

As all interviews were conducted by the author, a good understanding of the content of interviews was present from the outset of data analysis. Additionally, following each interview, reflections upon the content of the interview were written.<sup>xxiv</sup> Emergent ideas based upon participants responses during the interviews were also noted and written up following completion of interviews.<sup>xxv</sup>

All sixteen interviews were transcribed by the author which allowed new areas of interest to emerge from the process and transcription. Case notes were recorded and used both to inform questions for future interviews as well as to record preliminary thoughts on potential areas of interest for analysis.<sup>xxiv</sup> All interview recordings were clear and there were few problems in producing an accurate representation of the interview. In the few instances where there was a break in the recording, this was noted within the transcripts and the duration of the break, indicated.

Transcription was performed ‘non-verbatim’ in that all words spoken participants were recorded, but utterances such as ‘ummm, ahh’ were not noted. This approach was used as the aim of the research was to consider the content of participant responses, rather than to ascribe any potential meaning to *how* words were spoken.<sup>xxvi</sup> The validity of transcripts, was assessed by the by re-listening to the recordings and checking the text for accuracy.<sup>xxvii</sup> Further sensitisation was conducted by re-reading and annotating the completed transcripts to identify broad topics of interest for further analysis.<sup>xv</sup>

### **Step two: Free coding**

The development of thematic categories was undertaken using a two-phased approach to generate a thematic framework on which further analysis was based. In stage one, initial codes were applied to all transcripts. A ‘descriptive-coding’ method was used to identify topics of interest within the data.<sup>xxviii</sup>

This approach, involving continuous re-reading of the transcripts and noting passages of interest, may be termed a ‘pawing process’ in which numerous codes were applied to passages of interest.<sup>xxix</sup> Latent codes were applied with a view to understanding *meaning* within the transcripts, rather than simply reporting upon content.<sup>xxx</sup> Using this approach, a total of 286 unique codes were applied. Descriptive statistics of the prevalence of codes within transcripts were noted to identify common areas of interest, though thematic development was based more upon what was considered important, rather than what was prevalent.<sup>xxxi</sup> Furthermore, this approach ensured that novel views were fairly represented.

To increase the validity of this coding approach, transcripts were coded by an additional palliative care professional (CG) to determine whether the coding approach used by the first author was both consistent and accurate.<sup>xxxii</sup> This exercise demonstrated high levels of agreement in terms of the key issues being identified by the coding process. Common issues identified by both authors included; drug availability, human rights discourses, as well as the challenges and dangers relating to the transfer of policies and practices between contexts.

### Step Three: Development of a thematic framework

In line with the overall theoretical approach of the thesis, initial themes were developed based upon a Global Social Policy (GSP) understanding of global policymaking processes. Theme development was conducted by engaging both with codes identified as well as by returning to the original transcripts and field notes.<sup>xxxiii</sup>

Coded transcripts were consulted and relationships between codes and issues identified. Mind maps were used in order to draw out complexities and overlaps between such relationships.<sup>xxxiii</sup> For instance, several participants raised issues related to educational curricula and palliative care. It was not of interest to the study to engage with details of such curricula, in terms of ‘what drugs are recommended for the treatment of breakthrough pain’? Instead, what was of interest, were issues such as: in which contexts and settings would such curricula meet the educational needs of practitioners? Where have such curricula been used? And if such materials are transferred between nations, whether it was appropriate to do so and what modifications were made in order for curricula to be locally relevant? Additionally, themes were not determined by questions asked to participants and instead emerged from participant responses and their theoretical relevance.

It follows that many codes were relevant to more than one potentially emergent theme. For example issues relating to teaching curricula may relate to several distinct codes:

- Education – as curricula are a common way of setting educational standards
- Lack of Awareness – curricula as a response to a perceived lack of awareness of palliative care issues and treatments amongst students and medical practitioners
- Appropriateness – are curricula appropriate in all international settings, are the necessary resources available for the curricula to be applied in practice?
- Transferability – what are educational needs which are common between nations, and what elements of curricula require adaptation when transferring them between settings?

Thus, themes and sub-themes were preliminarily developed by viewing issues of interest to the participants through a GSP theoretical lens in order to answer the research questions using a deductive approach.<sup>xxxiv</sup> Several issues underpinned all emergent themes and to avoid undue repetition, these are only made explicit where necessary. For instance, in line with the overall aim of the chapter to consider how the global advocacy strategy can become more refined, almost all

emergent issues may be considered relevant to advocacy which consequently is not presented as a theme.

Additionally many relevant issues – for instance lack of access to essential medicines – may be present at local, national, international or global level, with resultant consequences for policy development and advocacy. Where such circumstances applied, differing approaches to address a single issue are presented for each level. Illustrative examples for how such an issue may be present at each of these levels are presented below.

**Table 17: Barriers to access to essential medicines at different levels of governance**

<b>Level of Governance</b>	<b>Illustrative example of barrier to access to essential medicines.</b>
Local	Lack of trained practitioners to prescribe and administer medicines.
National	National regulations prohibit access.
International	Lack of profitability of opioids to pharmaceutical companies, limits their willingness to supply.
Global	Access to opioid analgesics prohibitively regulated as a narcotic substance rather than enabled as an essential medicine.

In-keeping with the aim of completing a thematic analysis, themes were not developed based upon level of governance, however, the consequences of dealing with a ‘single’ issue at different levels and how the different levels interact are discussed.

#### **Step Four: Finalising the thematic framework**

Within any qualitative analysis, it is not possible to report on every issue of interest within the data collected. Thus, themes were structured by examining relationships between codes and in terms of being of most interest to the research questions.<sup>xxxv</sup>

A preliminary framework was developed before being reviewed by a palliative care expert (CG). Following discussions, thematic categories were refined and sub-themes reduced by consolidating

them within broader thematic categories. No explicit limit was placed upon how many themes were identified, nor how many sub-themes were appropriate within these broader categories. It was, however, acknowledged that it was neither feasible nor useful to attempt to report on a high number of sub-themes. Through discussion and by returning to the transcripts, some sub-themes were removed by incorporating them within broader thematic categories as examples. Additionally, through the processes of defining each main theme, some sub-themes naturally served as examples of relevant issues within such categories. In this manner, both themes and sub-themes were refined during an ongoing process in which original transcripts were re-consulted, to ensure that themes moved beyond narrative description into more meaningful analysis.<sup>xxxvi</sup> Finally, during writing, some thematic categories were amended in order to structure logical arguments in line with the act of writing itself being an important element of analysis.<sup>xxxvii</sup>

## **Limitations**

Although every effort was made to use robust qualitative methods, certain limitations must be noted of this element of the study. Risks associated with researcher bias were noted in Chapter Four and will not be repeated here. It serves to add that, during interviews, every effort was made to ask open questions in order to obtain authentic responses as opposed to asking 'leading' questions.<sup>xxxviii</sup> Moreover, as has been described, reflexivity was employed during the coding process, which was an ongoing process, involving self-reflection and discussion to ensure that the thematic framework developed reflected participants' views.<sup>xxxix</sup>

Given that the study has a global focus, an increased sample size would have further enriched the data. Specifically, it would have been interesting and appropriate to include participants from 'distinct' regions within continental boundaries. For instance, approximately 60% of the world's population lives in Asia and cannot be assumed to be a homogenous population.<sup>xl</sup> Therefore, it cannot be said that voices from India and Malaysia 'represent' the continent. It would therefore have been interesting to include a participant from the Middle East and particularly China. However, although representatives from all continental world regions were included within the sample, the study does not claim global representativeness. Instead, the study aims to enrich understanding of palliative care in global context by drawing upon the epistemic expertise of key palliative care experts.<sup>x</sup>

In this regard, it is important to acknowledge the issue of positionality during interviews and within the study sample. As described in Chapter Four, the researcher undertook ongoing reflexivity throughout the research process in order to maintain an objective position, examining palliative care as an 'outsider' and strengthen the validity of findings.<sup>xii</sup> However, it should be noted that all study participants were 'insiders' and advocates for palliative care, which means that any dissenting views opposing the further development of palliative care may not have been reported.<sup>xiii</sup> Findings must therefore be understood in this regard and the inclusion of a broader range of stakeholders such as policymakers and dissenters represents an avenue for future research. Therefore, whilst the methods utilised have been justified in detail, the results should be read as an interpretation of social reality, as opposed to a presentation of objective 'facts'.<sup>xiii</sup>

## **Results**

### **Thematic categories (n=6)**

From the wide-reaching data, 6 thematic categories emerged during analysis. In the following section, each of these themes is defined, before the analysis proceeds in greater detail and in response to the research questions.

#### **1. Education; Changing the Culture of Medicine**

This theme emerged as issues relating to education underpinned much of the data collected and related to both how palliative care has developed internationally, as well as how it may do so further. It examines the view that policymakers and medical practitioners lack the knowledge and skills required to provide palliative care, as well as a response to a lack of awareness of palliative care amongst the public, medical professionals and policymakers. Existing efforts to provide palliative care education are appraised, both nationally and internationally. Additionally, the theme reflects views that increased palliative care education can lead to increased palliative care practice as well as a cultural shift in medical practice. Palliative care education is discussed as a response to the broad perception that the medical practice, with a heavy emphasis on doctors as opposed to other health professionals, has become over-technical. Participants shared that view that the 'culture of medicine' focusses upon treating patients' illness at the expense of not caring for patients as individuals with needs beyond curative treatment.

Overall, the theme reflects the predominant view amongst participants, that there is a global lack of understanding regarding what palliative care offers which may be addressed through increased education at all levels of governance and healthcare. Finally, the theme examines processes of ‘international lesson learning’, in terms of how positive and negative ideas and practices are transferred from one national context to another.

## **2. Palliative Care as an Area of Global Need**

This theme explores the consequences which result from the global lack of palliative care services and lack of access to pain relieving medicines. It presents how palliative care experts understand and conceptualise this need, which is an important element of refining how arguments for greater roll-out of services can be made through advocacy. Different forms of need and their causes are identified within and between countries, relating to inequalities and inequities of access. Pitted against this global need, barriers to the field’s development at national, international and global level are examined. Such barriers are explored as well as participants’ views on how they may be overcome. Moreover, the theme looks at global forces which may be acting either to promote or restrict the further development of the field.

## **3. Broad Benefits of Palliative Care and the Consequences of its Absence**

It is well known that palliative care treats patients *and* families/carers as the unit of care. However, this theme emerged to reflect the diverse range of ‘benefits’ which participants suggested that palliative care can offer. ‘Benefits’ which may occur at individual, community and societal levels are reported. Incorporating discussions regarding ongoing stigma to both illness and death, the theme includes discussion with regards to how palliative care can help to improve such attitudes and, by doing so, create more resilient societies. Additionally, benefits are discussed for healthcare systems with regards to the feasibility of integrating palliative care as well as how palliative care can contribute to the sustainability of healthcare systems. Finally, the counterfactuals to the suggested broad benefits are presented, in terms of the consequences of *not* providing palliative care for all stakeholders. Importantly, almost all of the suggested benefits are shown to have a ‘time dependency’, in that they are reliant upon the introduction *either* early in the course of illness or as an end of life intervention.

#### **4. Prioritisation Within Health Systems and Organization of Services**

This theme emerged to reflect discussions surrounding the idea of prioritisation between different elements of palliative care as an intervention, national health system organization and global health policymaking. The theme places palliative care within broader global areas of health need in order to understand where palliative care lies in relation to other health priorities within developmental healthcare systems. Within the global context of competing claims for limited resources, the theme explores the economic viability of further rolling out palliative care services. Additionally, whilst the study has identified a clear preference for a public health approach to development, this theme examines the role of the varied actors within the private sector (private health systems, health insurers, pharmaceutical companies etc) as either enablers or barriers to further development of palliative care practices. Finally, the theme considers the merits of a reallocation/redistribution of health resources as a strategy for increasing resources for palliative care and from where such resources may come from.

#### **5. Global Policies, Leadership and Actors for change**

This broad theme emerged to reflect the range of actors who have the (potential) power to influence palliative care development. The different actors who operate for change in palliative care policy practice and development are identified. Furthermore, divergent views held amongst participants regarding the potential for global level policies to effect change are reported as well as the role which 'leaders' can play, at global and national levels. Questions are also raised with regards to the sustainability of pioneer-led models of palliative care. Additionally, this theme reflects the need for the palliative care lobby to make alliances with other global health groups and institutions in order to achieve wide-reaching and sustainable change.

Also within this theme, current global-level policies including the WHA palliative care Resolution and the potential role for civil society actors to hold governments accountable to their obligations are discussed. Moreover, the very appropriateness of global level policies to diverse regions of the world is considered including questions regarding which issues in palliative care are 'universal'. On this basis, the merits of adopting regional, rather than global, approaches to advocacy are discussed. This reflects the emerging issue, that although there are shared challenges for all world regions, a regional approach to policy development and palliative care leadership may be a more effective way

to promote palliative care. Regional palliative care organizations in all world regions are considered in terms of what unites each of these organizations and the differing challenges that they face.

## 6. Framing Palliative Care

How the argument for palliative care is made by international advocates is a central question of the study. As such, this theme emerged due to the varied 'frames' with which activists are using to advocate for palliative care, as well as new innovative ways in which they may be able to do so. The theme examines which arguments may be effective in influencing different global health actors and raises questions about the appropriateness of using certain arguments in all settings. Questions of how different arguments interact with each other are raised, such as the compatibility of different human rights claims (i.e. right to autonomy, right to palliative care and right to die). The relative strength of each argument is problematized in terms of their likelihood to effect the change that they seek. Additionally, the merits of adopting regional, rather than global, approaches to advocacy are considered. This reflects the emerging issue that, although there are shared challenges for all world regions, it is rational for different regions to approach them in culturally relevant ways.

### Theme One: Education: Changing the Culture of Medicine

*"Without... awareness, that could be from the public or from professionals, the development of palliative care cannot work very well." Physician, Europe (P10)*

Education as a broad concept, either implicitly or explicitly, underpinned almost all discussions with participants. A general lack of awareness amongst the public, professionals and policymakers of palliative care and pain treatment was suggested throughout interviews. Additionally, there were strong views that such stakeholders have negative attitudes towards illness and death, perceiving them as unnatural processes which can be halted. Such attitudes appear to filter in to global discourses on health, which uses militaristic language when speaking about illness, suggesting that it is something which must be *fought*. Discourses such as 'war on cancer' are consistent with how current medical practice operates, which it was suggested is *too* focussed upon treating specific illness with curative intent, at the expense of caring for patients. That is, that the medical profession has become enmeshed with narratives which see death as a 'failure of medicine', and not part of the life course. What united all of these issues between participants was the strong suggestion that the

negative consequences of each of them may be addressed through greater palliative care education. Additionally, although the theme generally challenged existing practices of doctors, innovative suggestions emerged regarding how nurses may be empowered to deliver pain medication in order to increase access – particularly in rural areas.

However, a further issue of interest which emerged during discussions, related to what palliative care actually *is*. Divergent understandings, most specifically regarding the timing of when palliative care becomes relevant, were common. Additionally, it emerged that ongoing issues regarding the use of diverse terms – such as palliative care and end of life care – continue and threaten to undermine the clarity of the message with which the palliative care community hopes to increase ‘education’.

### **Competing definitions and understandings of palliative care**

Reflecting known problems regarding how to define palliative care, it was apparent during the interview process that when referring to ‘palliative care’, participants used the term based upon conflicting understanding of its meaning.<sup>xliv</sup> The major discrepancy in understanding arose regarding the timing of when palliative care should be introduced. One participant who had experience of working in both Africa and North America, commented upon this, raising concerns about how such divergent understandings impact upon the clarity of the message being given to global policymakers:

*“I think in Africa, unlike the West, palliative care is seen as applicable from the point of diagnosis... we [Africa] are looking at palliative care beyond end of life care. If you look at the west, they are looking at palliative care as end of life care, as really linked with end of life care, so there is a conflict there for us to resolve as a global community, what are we talking about?” Activist, Africa (P16)*

It was not clear whether this was an issue of understanding or of palliative care in practice, however, it did become evident from ‘Western’ participants, that palliative care was something which was generally introduced as an intervention much closer to the end of life than from ‘diagnosis’.

Such responses from participants at times appeared to reflect their own views and at others are suggestive of the circumstances within which they work. However, whether fuelled by an association

with palliative care as an intervention towards the end of life, or practical reasons such as late referral, certainly, there was a high prevalence of references to the deteriorated condition of patients presenting for palliative care in western settings. In Australasia, for example, one participant commented:

*“People can be suffering a long period before palliative care gets involved, symptoms can be unremitting, conversations have not occurred about death and dying and I think it does require a much more whole of medicine approach.” Physician, Australasia (P14)*

This quote is also supportive of a broadly held view amongst participants, that medical professionals lack awareness of what palliative care is, what it hopes to achieve and how it should be delivered, in short, a lack of education. Such issues are addressed further in subsequent sections.

It is, however, important to emphasise that there was a broad consensus regarding what the goals of palliative care are. Interestingly, although palliative care research often uses outcome measures relating to ‘quality of death’, it was improvement of quality of life which occupied most of the discussion in terms of what palliative should aim to achieve, centring around a shared goal of meeting the treatment goals of patients and families. In support of this suggestion, this quote from North America is illustrative:

*“The main benefits are that people get more appropriate care, you know, they get care that’s more tailored to the goals they have for care, and if you take the time to help patients and their families work out what their goals for care are, then you usually make better decisions, than if you’re just going, one thing after another, treatment wise.” Physician, North America (P03)*

Additionally, it is important to note, that the only patient voice within the study was supportive of such a conceptualisation of palliative care:

*“As I understand it, palliative care offers an improvement in quality of life, which means, that whoever is caring for someone who is having palliative care, their quality of life will improve as well.” PPI Representative, Europe (P11)*

Aside from divergence on the appropriate timing of palliative interventions, there was implicit unity

amongst participants regarding the principles of palliative care with which activists should seek to educate stakeholder groups. However, to some extent this unity of understanding is undermined due to conflicting terms used within palliative care. Indeed, in the global sense, the clarity of the message with which palliative care seeks to educate people faces problems quite literally 'not speaking the same language'.

### **Importance of terminology**

There was broad consensus amongst participants that the WHO definition of palliative was both appropriate and meaningful. However, there was acknowledgement of the confusion caused by the use of conflicting terms within the field which are sometimes used as synonyms for palliative care and at others, to describe something quite different. As most participants expressed doubt as to how well palliative care is generally understood, the use of consistent terminology emerged as an important issue:

*"People didn't really understand when I said 'palliative care', 'what are you talking about?' Just like everyone understands what Oncology means, what paediatrics means, what geriatrics means, we have nothing for palliative care. We have got palliative care, hospice care, supportive care, end of life care. That crucial terminology carries so much meaning".*  
Physician, Asia (P05)

In this regard, there was some suggestion that the WHO definition is somewhat technocratic, which may limit its usefulness for engaging with lay audiences. One physician from Asia, for example, quipped:

*"It's very simple, if you look at how you define palliative care, I mean the WHO, you know, I mean the latest definition is about 10-12 years old, talks all kind of stuff about impeccable assessment, blah blah blah, but according to me, it's basically, good medicine, sorting out issues of the person, not the patient, I'd like to call it the person" Physician, Asia (P04)*

Evidently the point was made in a somewhat blasé fashion, however it does raise the issue of whether the WHO definition is meaningful to non-clinical audiences. However, the more prevalent issue identified during the interview process, related to terms competing with palliative care, with a consequent reduction in clarity of meaning, especially within non-English speaking settings:

*“I accept the World Health definition, and it says palliative care...but where does that leave this term ‘hospice’? ...Until the World Health had the palliative care definition, hospice existed for twenty thirty years before that, and although generally we say palliative care and hospice are synonyms, in reality, they are now not seen as the same.... Changing from hospice, to palliative care, to supportive care, we actually have no words for any of those things, so what do we call our services?” Physician, Asia (P05)*

With public understanding of what palliative care so low around the world<sup>xiv</sup>, use of overlapping terms such as ‘palliative care’ and ‘end of life care’ raises questions regarding the key message of ‘palliative care’ as to whether the term should have a predominant focus upon quality of life, or quality of end of life care.

It is important to acknowledge, however, that amongst participants, distinctions between quality of life and quality of end of life represented more of a difference in emphasis than principle. A clear commitment towards facilitating positive experiences for patients and families at the end of life was evident amongst all participants. However, when considering how to improve the understanding of public and professionals, there was no identifiable abandonment of the will to improve attitudes to illness and death by leaving them out of the conversation. Instead, it was suggested that by focussing upon palliative care as ‘quality of life’ rather than ‘end of life’ that improvements in experiences at the end of life may be made naturally and not by confronting the issue directly. One palliative care physician reports on how this has occurred within his own national advocacy campaign:

*“In many countries, discussion on death is such a taboo issue, and hence, in my own country, we have eliminated virtually all, consciously eliminated all talk on terminal care, and dying, in the sense that, we need to look at suffering and improve quality of life, and let the issue of death worry about itself.” Physician, Asia (P05)*

In summary, in spite of broadly shared *principles* regarding what ‘palliative care’ is and when it should be introduced, it remained a contested term amongst participants. Some of this confusion may stem from the fact that the WHO definition has changed, in the sense that it is only fairly recently that palliative care was recommended from diagnosis rather than closer to the end of life. Nevertheless, it is of concern for the clarity of message which advocates can hope to deliver to new stakeholders, that confusion remains regarding the meaning of the term itself. Indeed with this lack

of clarity emanating from key experts in palliative care, it is perhaps understandable that within the broader culture of medical practice, awareness of palliative care appears to remain low.

### **Palliative care within current medical practice**

There was a high degree of consensus amongst participants that there is a lack of awareness of palliative care amongst medical professionals. Although the study did not include any medical professionals from outside the field of palliative care, participants seemed to share a negative perception of the medical profession in terms of how doctors, as opposed to other health professionals, treat patients during serious illness and towards the end of life. Participants tended to perceive medics as being focussed upon a technical approach to curing illness, at the expense of treating patients as people and caring for them as such. The following quote sums up quite succinctly this broad perception as well as how such a situation may have occurred:

*“So many advances in medical practice, clinical practice, and high-tech, methods of dealing with disease, has meant that people are living a whole lot longer, but our medical schools focus on cure, with very few actually look at the softer skills that require, that are care and the actual impact that happens when, when a person has got a life-threatening illness.”*  
*Physician, Africa (P07)*

This perception of the ‘treatment culture’ of medicine was not isolated to any one world region. Indeed, participants from all regions strongly suggested that often a medicalised approach continues beyond a timeframe in which curative efforts could hold the possibility of being effective. Referring to the dying-phase, one participant suggested:

*“People who are dying at the moment, they are treated in a very technical way. They keep irradiating people with cancer, people with other diseases, they try to heal the disease, but not or often, doctors and healthcare more generally, ignores the symptoms and to relieve the suffering that comes with it.”* *Pharmacist, Europe (P01)*

Two major reasons were suggested by participants for this cure-focused scenario: 1) lack of awareness of palliative care and 2) structural pressures upon doctors to maintain curative efforts even when they are unlikely to be effective. It is therefore important to consider the broader context

within which medical practitioners work and how patients, hospitals and society more generally, expect doctors to approach illness.

### **Death as failure**

Whilst participants broadly shared the view that physicians are often culpable of providing inappropriate care during the terminal phase of illnesses, it is important to emphasise that this was not intended to be criticism of individual practitioners. Instead, there was criticism of the wider structural context in which practitioners were situated. There was acknowledgement, for example, that practitioners work within an ideational context, in which militaristic language can sometimes be used when speaking of illness:

*“Unfortunately... the medical students are taught, it’s almost like it’s a battle that they need to win. In fact, the other day there was an article I read, where somebody was lamenting, ‘why do we use words which are related to war?...’He lost the battle to cancer’...’we will use all of the ammunition in our hands’, you know.” Physician, Asia (P04)*

Such language filters in to attitudes and practices of medical professionals, and indeed public attitudes more generally. It follows that fears and negative attitudes towards illness are reinforced, leading to perceptions that the death of a patient is treated not as part of the natural process of life, but as a *failure* of medicine:

*“Medicine and physician was wrong in the last years and has abandoned the patient when the patient cannot be cured when the patient cannot be the object of the success for the physician” Physician, Europe (P10)*

Such situations see aggressive curative treatments maintained beyond the point where they are likely to be effective. In line with this, a broad lack of awareness amongst practitioners as to when and why palliative care should be introduced was an issue voiced strongly by many within the study. An oft-used example by participants was the appropriateness of chemotherapy for advanced cancer, as opposed to palliative care. Whilst this reflects an implicit division between curative efforts and palliative care, it remains illustrative of the preference within medical practice to maintain aggressive treatments at the expense of palliation. Yet, as was also identified within Chapter Five, little is known regarding patient preferences in such circumstances. Referring to patient preference

with regards to ongoing chemotherapy or palliative care towards the end of life, one participant promoted both increased communication between physicians and patients and also lamented the lack of research on patient preference:

*“If the patient knows that he is at the end of life, he doesn’t prefer chemotherapy, but the question is, who is dealing with the truth with the patient, who is asking the patient ‘what do you want?’ Physician, Europe (P10)*

An apparent consequence of failing to determine patient treatment preference and a lack of recognition of palliative care as an appropriate intervention is that medical practitioners do not present palliative treatments to their patients as an option. Thus, within hierarchical relationships of power, coupled with a lack of awareness amongst the public and professionals, curative treatments were perceived to be presented to patients as the ‘only option’ without consideration of the benefits that a palliative approach may hold. In such circumstances, patients may forgo their autonomy in relation to defining their own health pathway on the basis that people cannot request something which they do not know about. However, the extent to which patient populations are *willing* to endure high amounts of suffering with a vain chance of cure is unknown.

One consequence of over treatment is an increased burden of suffering upon the patient due to ongoing futile treatments.<sup>xlvi</sup> Indeed, such circumstances certainly appear to add weight suggestions that physicians do not always have the requisite skills in order to reduce overall symptom burden whilst they maintain focus upon *curing* that illness. One physician from North America reflected upon his experience of the condition of patients presenting for palliative care in his institution:

*“People come to us, and oftentimes, they look like a train wreck, I mean, they look like they’re going to die soon, and as we get them sorted you, get their symptoms controlled, get them, you know, get their bowels working correctly... wash them up... and they start to feel good” Physician, North America (P03)*

Why then, do physicians continue with curative efforts beyond a stage of illness where they are likely to be successful? At this point, it is appropriate to switch the focus away from the awareness of physicians, towards what they may be expected to know, based upon their medical education.

### **Doctor training and curricula**

A prevalent issue which emerged during discussions related to the relative absence of palliative care and symptom management training within undergraduate medical training curricula. This issue may be considered an important one due to the strength of feeling apparent amongst participants regarding this situation:

*“How we can accelerate the development of palliative care?... several answers are possible, but I only have one answer for you today.. The answer is, train physicians in the school of medicine, that’s your answer” Physician, Europe (P10)*

Several participants reported that appropriate curricula exist, but a lack of integration into broader medical curricula as well as a degree of tokenism towards important skills such as pain management is the problem. For example, speaking about one European country and the attention which is paid to pain management within medical training, one participant reported:

*“Even if it’s included in the curriculum its often just for a few hours, not enough to learn how to treat pain...in Hungary there was someone who went over this for various medical specialties and it was always between three and twelve hours... and they also looked at veterinarians and they get between 34 and 40 hours.” Pharmacist, Europe (P01)*

This is a troubling comparison and a convincing example of a broad lack of awareness of the importance of such skills within medical practice. Indeed, given the emphasis placed upon education as part of the WHO’s public health strategy for palliative care development<sup>xlvii</sup>, it is of great concern that one participant reported on a study of medical schools in Western Europe and found:

*“There were universities where they did not have any pain treatment in the curriculum” Pharmacist, Europe (P01)*

Through such conversations, it emerged that lack of education amongst physicians continues to serve as a major barrier in terms of patient access to pain treatment. Often, opioid availability is defined as a problem relating to how medicines are regulated. However, even within countries which do not prohibit access to medicines such as morphine, there were real concerns that medical professionals did not have the requisite knowledge and skills to prescribe them appropriately and that suitable guidance was *not* available:

*“[The] problem is that there is a lot of doctors [that] don’t learn how to titrate patients, or dose the analgesics, and also if you go to textbooks, often it’s wrong or incomplete. For instance, there’s hardly any textbooks saying that for unsupervised patients, you should never increase the opioids more than 50% in 24 hours. The starting dosages are often too high for unsupervised patients and there’s not any textbooks saying to stop in a way that you avoid the withdrawal syndrome”. Pharmacist, Europe (P01)*

Furthermore, in terms of guidance available to a global audience, there were additional concerns regarding the relevance of current pain management guidelines. As one participant commented:

*“The problem with not having guidelines is of course, at the moment, the only book you have is ‘cancer pain relief’ which is the 1987 guidelines, and when you’re advocating for pain relief, for palliative care and saying it’s also for HIV/AIDS patients. So, you need, as WHO, to have guidelines that are broad, and cover everything and as long as you don’t have that, then many people apply the three-step ladder for all types of pain and I think that scientifically it’s correct, but legally, these WHO guidelines are only looking at cancer pain”. Pharmacist, Europe (P01)*

Yet, amidst such concerns, many positive stories arose of educational efforts. However, positive examples often served to highlight how variable educational initiatives are, both internationally and within countries. Reflecting upon the extent which palliative care education provided to undergraduates has improved and lengthened within their institution in Australia, from a single day session, one participant reported:

*“...Now we have a full week with the students, so we immerse them, we go on ward rounds, we talk, I speak to them about the care of the dying, which is the only lecture they will get in their undergraduate degree on that topic, and then also just the sense of our perspective in terms of communication, symptom management and all of that, and they, universally they find it revelatory” Physician, Australasia (P14)*

However, even in Australia, which was cited by one participant as having “*well, integrated palliative care strategy in its health agenda, health budget and health education [Physician, South America (P09)]*”, the Australasian participant conceded that provision of palliative care education to

undergraduate students was 'not universal' within medical schools. Although the apparent acceptability of the training to the medical students was positive, due to the importance that many participants within the sample placed upon the integration of palliative care education into medical curricula, the patchiness in educational provision is a concern.

Despite this, examples emerged from diverse contexts where integration of palliative care into the medical curriculum is occurring. For instance, in Uganda, it was reported that education is "*the model for sustainability*" [Activist, Africa (P16)]. Furthermore, integration was considered to be something which may not only further the development of palliative care, but which may serve as a driver for change against the technocratic culture of medicine:

*"If we don't normalise palliative care in the health [education] of the future physicians, we cannot try to change the way to do medicine 10 years later, first, we have to teach physicians in the school of medicine"* Physician, Europe (P10)

Although the importance of integration was emphasised by participants, there was some acknowledgement that this required national strategies for palliative care development. Yet, in spite of the acknowledged importance of integration into medical curricula, this was not the dominant reason expressed amongst participants with regards to how palliative care has spread internationally.

### **International lesson-learning**

Many participants within the study reported that they had been trained in palliative care in a context other than that in which they originated from. For example, one representative from Asia trained in the United Kingdom, whilst a South American participant trained in the United States. Additionally, participants discussed international educational initiatives, whereby institutions in different nations cooperated to offer accredited palliative care courses. Central to such discussions was the distinction between elements of palliative care practice which are 'universal' or appropriate in all national contexts, and elements which require adaption within different settings. A clear example of such distinctions arose regarding pain management. One participant, who reported on their experiences in conducting palliative care 'sensitisation' courses in a wide variety of settings explained:

*“If I’m doing pain management for example, the pharmacology is the same, the approach to assessment is the same, teaching that, what’s different is, ‘what drugs do they have?’”*

*Physician, North America (P13)*

What this describes, is that individuals in any setting respond to pain treatment in a universal way, however, educating medical professionals on how to prescribe and administer opioids is only appropriate if medicines are available to practitioners. Pain medicine serves as a relatively straightforward example regarding the appropriateness and transferability of key skills and practices due to the universality of physiology. More complex issues arose relating to transferability of more cultural aspects of palliative care:

*“If you’re doing communicating bad news, negotiating goals of care... principles are the same, what you have to do is to find out, ‘what are the ethics, that guide clinical care, as well as laws that exist in a country?’ and you need to adapt all of that to that setting.”*

*Physician, North America (P13)*

This quote echoes a response reported above, whereby it is suggested that there is a need for palliative care guidelines to contain both universal principles, along with the flexibility for them to be adapted to local context.

Through discussions of the example of pain management education, the potential for damaging (as well as beneficial) lessons to be taught when educators work in other settings was revealed. Such issues arose in two distinct ways. One participant reported upon their perception that in the Asian setting, when palliative care doctors came from Western settings, that there was a tendency for Asian doctors to accept their opinions with undue reverence:

*“There’s a perception for example, in some low-resource countries, that an expert in England or North America or somewhere, would be seen as a more, as a more acceptable, knowledgeable person than someone from their own country. ‘The Foreign Expert’”*

*Physician, Asia (P05)*

Of greater concern, however, was the suggestion that Western clinicians visit low-resource settings under the guise of lesson-sharing, but with the additional motive of promoting specific pharmaceutical products for their own benefit:

*“Someone from UK comes over [to] Malaysia as a palliative care person and says “this is what we use in England, I like this product, it’s wonderful’... I think that’s where you have the ethical and moral imperative. Does that, is that right for a person in UK to come over to a low-resource country and tell them what to use, especially under the guise of a pharmaceutical product. They’re invited, they’re often paid [by the pharmaceutical companies] it’s a sales pitch!” Physician, Asia (P05)*

Indeed, whilst it was evident that many positive changes have occurred due to processes of international lesson-learning, such narratives were often couched with words of caution. Another participant reflected upon the dangers associated with the ‘unintended consequences of medical missionaries’ and offered suggestions of how the negative effects of short-term programs can be mitigated:

*“You can’t go just once, you have to have a strategic plan ... I want to know what the people are doing in follow-up from the courses I’ve run, if people who are coming to my larger programs, I want administrative commitment that these people are going to be hired. There’s only so far I can go, I can’t demand that people have morphine, unless they want the course in the country, in which case I can say, ‘well I need to have morphine in order to run the course, I won’t run the course without morphine’, because it’s stupid to go into a course and teach things, go into a country and teach things, which people can’t practice next week. It’s actually stupid.” Physician, North America (P13)*

Whilst the ethical tensions associated with processes of international lesson-learning warrant consideration, overemphasis on such dangers risks undermining the many positive examples of international educational processes which have led to major progress in palliative care development. Many services in low-resource settings were described as having their genesis from local researchers travelling to other contexts to learn about palliative care. For instance, one physician from South America described how their experience of palliative care in North America led to the establishment of the first hospice in their home country:

*“I went to school...in the US and then I went back to [country] after doing my undergraduate degree ... I did clinical psychology and neuro-psychology and that’s how I ended up working in the pain field, but then I went back to [country] and I realised that what I had seen in my training, was not available because of several issues, one of them was, no access and no*

*availability of medications and the second one and very important one was the lack of education” Physician, South America (P09)*

Additionally, although challenges were reported associated with resource context, the participant also described a more symbiotic experience of lesson learning, through discussions of how transferal of ideas between settings can have positive benefits for both sides. One beneficial lesson for low-resource settings was the relationship between medical professionals and patients:

*“You also have the issue of patient autonomy which in the rich countries is I think more defined and better respected, or at least more respected in developed countries, in developing countries this whole issue of patient autonomy and patients as part of the decision-making process, at least when I was there, it’s almost non-existent and you have a very vertical model of...the physician making decisions and then the nurse implementing the decisions and the patient accepting, and taking whatever, it’s been ‘ordered’” Physician, South America (09)*

For high-income settings, it was suggested that the involvement of a greater amount of stakeholders in the delivery of care was something which richer settings do not have, to their detriment:

*“You have a lot more involvement from the community, a lot more involvement of the family and there’s a stronger, I think, should I say ‘community approach and holistic approach to the care of the patient rather than what you see in the rich countries’ the rich countries are more, much more individualistic about addressing the very specific needs of the patient in a very, you know, self-centred and patient-centred approach, and what I’ve seen from working in Colombia is that it’s a more community-based approach, and it’s a whole unit of care” Physician, South America (09)*

Once more, this negative suggestion of a technical approach to patient care carries with it warnings regarding the transferral to other settings of a technocratic approach to medicine. Thus, processes of international lesson-learning hold the potential to both further the development of palliative care in all settings, as well as for the spread of less beneficial ideas and practices.

Lastly, although it was the attitudes and practices of doctors which emerged as a key barrier to the delivery of palliative care, the potential for an increased role of nurses in the delivery of pain medicine was identified as a key way in which access to pain treatment may be increased.

### **Empowerment of nurses**

The potential for nurses to play a key role in increasing access to palliative care and pain medication was not a common suggestion amongst participants. However, as in many world settings people suffering from illness will never see a doctor and will be cared for solely by nurses, the proposal to educate nurses to be able to prescribe pain medications appears a rational way of increasing access to appropriate care.

In most medical settings, nurses do not play a role in the prescription of medicine, however, in Uganda nurses are being educated in order to prescribe and deliver strong pain medication. There are few doctors in rural areas of Uganda, but there have been increases in community health programs, which have increased access to nursing services:

*“If we want palliative care to be provided at home, and if we want to control pain and only doctors can prescribe pain medication because it’s an opioid, and 60% of the Africans, or people having palliative care may never see a Doctor, it means you’re automatically excluding 60% of patients from accessing pain medication, because the person seeing them cannot prescribe. So make the case about task shifting” Activist, Africa (P16)*

Furthermore, the relative ease with which nurses may be empowered to medically treat pain as opposed to training doctors is significant:

*“For you to train these doctors, it takes about five years to train them, you train these doctors for five years, it costs so much [whereas] If I can invest, nine months, because the clinical training for nurses is nine months, if I can spend nine months and train these nurses, after nine months, they are able to do clinical assessment of pain, clinical prescription of pain without supervision, whatever costs worth [it]” Activist, Africa (P16)*

This example hints not only at additional economic benefits to health systems, but shows the feasibility of educational programs to train nurse prescribers. In this regard, the empowerment of

nurses appears to offer real potential to increase the reach of palliative care services. Indeed, although this example refers to Africa, a low-income setting, access to services in rural areas is a known international challenge.<sup>xlviii</sup> Referring to Australia:

*“As soon as you move away from the settled areas, the number of palliative care physicians, are much more limited, and very much it’s, it’s very much in the hands of local family practitioners, and also, palliative care nurses.” Physician, Australasia (14)*

This theme revealed most strongly, the need to challenge the existing culture of *medical* practice through doctor training. However the potential for an increased medical role of nurses represents a practical way of challenging this culture. Moreover, the apparent feasibility of nurse-training aimed at increasing overall access to pain medicine appears one worthy of serious consideration. However, the extent to which the suggestion is acceptable to nurses, who already face high workloads and pressures, was not revealed during discussions.

## **Theme Two: Palliative Care as an Area of Global Need**

Although by nature of their participation in the study, it may be suggested that all participants had a shared view that there is a global need for palliative care, this viewpoint was not assumed during interviews. As such, participants were asked to reflect directly upon the question of ‘why do people need palliative care’? Understanding participants’ views on this question is extremely important in terms of the clarity with which current advocacy strategies are presenting an absence of palliative care services as a ‘problem’.

On being asked ‘why there is a global need for palliative care’, many participants responded in terms of statistics. As one participant noted:

*“We attempted to define the need for palliative care for adults and children, using somewhat conservative methods for, from WHO, it’s a WHO publication, so we had to go by the rules which were risk averse, and anyway, the global need was estimated at 20 million at the end of life and 40 million if you count people prior to the end of life, which again is somewhat, probably conservative.” Physician, North America (P03)*

Whilst there is perhaps an issue of semantics here, the statement arises from an assumption of need,

and is not a description of *why* people need palliative care. Many respondents conceptualised the need for palliative care in terms of an antidote to issues emanating from current medical practice, as discussed in Theme One:

*“Why we need, why we have today a global need of palliative care and not in the past? Hundred years ago, physicians were at the side of the patient, at the side of the family, caring him, speaking him, attending the family, attending the suffering, with humanity, but not today.” Physician, Europe (P10)*

Other respondents presented the need for palliative care counterfactually; that is, that the problem was often presented less as ‘people need palliative care because...’ and more in terms of ‘this is what will happen if people do not receive palliative care’:

*“It’s the burden of suffering, not just the burden of pain, but suffering, so... without palliative care the burden of suffering would be a lot higher.” Activist, Europe (P02)*

Finally, the one Public Patient Representative within the study, concurred that there was a global need, and used an example of one person who was admitted to hospital with terminal lung cancer in the final stages of life and was left without pain treatment, stating:

*“It’s just humane, it’s wrong to leave people suffering, just wrong” PPI Representative, (P11)*

Presented in this manner suggests a moral imperative to address the suffering of people wherever it is feasible to do so. Indeed, many participants emphasised the word ‘suffering’ in terms of why people need palliative care. As demonstrated, the suggestion that there was a ‘global need’ for palliative care was shared by all participants. The full consequences of absence of palliative care services for a wide variety of stakeholders will be examined alongside the potential benefits it may offer in Theme 3. Firstly, however, the following section examines the wide range of factors which serve to limit access to pain and palliative care services.

### **Inequality and inequity of access to palliative services**

Inherently tied to the suggestion that there is a global need for palliative care were discussions regarding access to services. On this basis, it is necessary to determine the factors which determine access (or lack thereof) to palliative care. Often, the clearest reasons were described in terms of known problems such as lack of services and non-referral by medics to palliative care services.<sup>xlix</sup> However, it was notable that during discussions regarding ‘access’ discussions often moved somewhat interchangeably between ‘access to palliative care’ and ‘access to pain treatment’. For instance, the only Pharmacist interviewed within the study, described international inequity in terms of upon access to pain treatment:

*“In three quarters of the world or over, people hardly have any access to opioid analgesics, so they are not treated for their pain.” Pharmacist, Europe (P01)*

Reporting a similar story, a physician and activist from Europe, summed up the need for global development based upon egalitarian principles:

*“There is a strong inequity between countries, if we look at the development of palliative care, palliative care is more developed in countries with, more rich countries and less developed in countries with low incomes... Then why do we need the global development? Because we have very partial development at this moment, very very very partial development...” Physician, Europe (P10)*

What both quotes represent, are moral arguments for the extension of pain and palliative care services within poorer regions where services are less developed. The suggestion is that it is unethical for access to services to be determined by the wealth of the nation in which you live. Developing this argument, access to pain treatment and palliative care may be considered ‘comparative needs’. That is, globally speaking, within groups with similar characteristics such as a serious illness, some are not receiving the same level as care as similar groups who are. This inequity exists both between countries as well as within them however, the narratives of inequity within countries ran counter to that presented for the international context.

Unusually, whereas internationally, the example suggests that it is richer nations which have better access to palliative care, some participants reported that based upon their experiences, it was actually poorer sections of society which had better access to palliative care. Perversely, this inequity which poorer people benefit from, stems from financial inequality, whereby those with the

resources will seek cure 'at all costs' whereas, poorer people benefit from not being able to pursue such paths:

*"Poorer sections of society may access palliative care earlier [in India], and sometimes I feel I, I hate to say this, but sometimes I feel like they're lucky you know, because of the fact that they would have landed up in the same state, but they would have spent far more money which they cannot afford, and many many families sell their land, sell their house because they want to save their loved one... I don't want to sound presumptuous...but I think that sometimes, being poor helps you. The guy who is able to afford, and he's able to afford a lot, he's got very deep pockets, I think ultimately, it's sad but he will suffer more, because he's running after a chimera, running after a mirage." Physician, Asia (P04)*

The issue of out-of-pocket expenditure will be returned to in due course, however, not only does this quote relate back to discussions presented above relating to attitudes to illness, it hints at something else. It was suggested that there is a perception that if something costs more, then it is 'valuable.' This means, that people may be willing to spend a lot of money in the pursuit of cure where it is feasible – even if the cheaper alternative may be more appropriate. Expanding on this issue:

*"I've potentially had better satisfaction dealing with people who are very poor than those who are very rich... Because I find that you distil the issues of life and death into what truly becomes most important, to them, which is usually the values that they live by, whether it is family, being forgiven, being loved, being honest, being truthful and I find that those values reside so much better in those that have got less material wealth. The perception in Malaysia and I think in many, some other countries, is that palliative care is for the poor, it's not for the well off. 'I don't need palliative care yet, I still have potential resources to deal with the disease'" Physician, Asia (P04)*

However, although the suggestion that poorer people are more likely to access palliative services than richer groups, this was not a consistent narrative amongst participants and indeed there was variation even when discussing the same country (India). There is a clear rationale for the suggestion that poorer people access services due to financial limitations. Yet, a different factor relating to finance centres arose around access to pain treatment:

*“In India you know there were some states that would have fentanyl patches but they did not have basic oral morphine pills, and so the pharmaceutical industry was basically taking care of all of the regulatory nonsense... in order for the fentanyl, but they were not doing the same for the oral morphine tablets, and so as a result, the expensive medications are available, whereas the inexpensive medications are not available.” Physician, Asia (P04)*

Thus, unusually, socioeconomic status of patients was considered to act as both enablers and limiters of access for different social groups. However, socioeconomic status was not the only determinant of equality of access. With palliative care professed to have benefits for all patient groups suffering serious illness, many participants suggested that services are more commonly available to cancer patients rather than patient groups suffering other illnesses:

*“In my country, mainly, the patients that are receiving palliative care are cancer patients and we know today that at least over half of the amount of patients that are in need of palliative care, are non-cancer patients” Physician, Europe (P10)*

This focus upon cancer has its roots in the history of the development of palliative care.<sup>1</sup> Furthermore, this disease-specific association is strengthened by the aforementioned existence of global guidelines for treating cancer pain only. Consequentially, this focus upon cancer exists in many world regions. Indeed, only one participant, based in Africa, described palliative care services which appear more responsive to other illnesses and changing disease burden:

*“If you [look] at Uganda for example, the key patients who are accessing palliative care, this has shifted as the disease burden shifts, things shift, so initially in the 1980s it was the cancer patients, you know, really chronically ill patients with cancer, that was maybe 80 percent of the people accessing palliative care in the 80s. In the 90s, the balance shifted and [now] it’s more the HIV/AIDS patients.” Activist, Africa (P16)*

Nevertheless, we may describe people living with serious illnesses other than cancer as having a comparative need in relation to cancer patients. However, within discussions, what united participants was the perception that patients of all diagnoses represent a marginalised group within health care systems.

Understanding people living with serious illness as ‘marginalised’ is a complex issue. The label holds the potential to both raise awareness of suffering caused by illness, but also risks further marginalising such populations by increasing stigmatization. Speaking of the receptiveness of donor organization United States Agency for International Development (USAID) to rights-based discourses, one participant from Africa indicated:

*“When you look at their definitions of marginalised groups, they are talking about sex workers, they are talking about lesbians, they are talking about gay, that, you know, that type of grouping, so the palliative care, are also not very keen to have the palliative care patients to be put in that category of marginalised populations, or most at risk populations, because then it could cause stigma for them, so that’s kinds of a conundrum.” Activist, Africa (P16)*

Additionally, it may be suggested that there is an unequal distribution of suffering amongst the general population, and consequently, a societal responsibility to mediate the negative effects of illness. Indeed, it is of great concern, that beyond inequalities of access based upon diagnosis, further inequalities were identified based upon *age*, stemming from lack of education and access to medicine:

*“The suffering that children have because people don’t have the skills and the knowledge, and often medicines which are available are not in paediatric formulations. People don’t know how to do pain assessment, symptom assessment in children, and for all those reasons, children’s palliative care has been left behind. It’s the Cinderella of palliative care” Physician, Africa (P06)*

A key focus of discussions relating to access to pain and palliative care services, were issues, or ‘barriers’ to such access. Barriers were identified at both national and international levels, and in the following section, factors which are perceived to act as limiters – as well as enablers on access to services are reviewed, with a focus upon access to pain treatment.

### **Barriers to access and further development**

Barriers to pain treatment were identified within nations, influenced by both international and national-level factors. How international drug policies and regulations influence access to pain

medicine will be discussed in Theme 5. Here, however, the focus shifts to how national-level policies and circumstances serve to limit access – even in countries where regulations permit the use of strong pain medicines.

Significant regional variation was identified in terms of national-level barriers to pain medicine (although some issues do overlap). Commonly, it was reported that in low-income settings, issues of national regulations, resources and education can interact to limit access, whereas, in higher-income settings, discussions focussed more upon lack of prescribing due to fears regarding misuse of strong medications. In terms of regulations and education:

*“We often see that the core medications we use, the opioids, the anti-psychotics, Haloperidol, the benzodiazepine, which we use for management of terminal delirium, and a few of the other medications, they’re often of very restricted use. They may be in the country, but the people who need to be able to prescribe them, can’t.” Physician, North America (P13)*

This quote is suggestive of regulatory limitations upon strong opioid use. Additionally, it may be understood as indicating a lack of education amongst physicians regarding how to prescribe strong medicines, a view shared by many participants and supports the idea that it is not simply regulatory issues which limit their use within countries as identified here:

*“We could suddenly liberalise all of the opioid laws around the world, which would be miraculous, but then you’d have the next challenge, for doctors and nurses who have not used those medicines, or have barely used them, to be, to be skilled and not ‘opiophobic’... or opioid ignorant in their ability to use them” Physician, Australasia (P14)*

More positively, evidence emerged regarding how access to pain medications is increasing through more enabling regulations. In India for instance, it was reported how prohibitive regulations had been overcome through advocacy:

*“In the good old days, you required six licenses before you were able to get morphine.... So by the time you have got the third license, your first license would have expired. , a couple of individuals realised that the government had the authority to take back the powers of legislation, on these multiple licenses from the State Government back to itself... and we*

*lobbied for that and the government realised and we've put some excellent bureaucrats in place... so now, the law has been amended" Physician, Asia (P04)*

Furthermore, in Uganda, it was reported that access had been increased through enabling regulations, as well as by equipping nurses with the skills to prescribe as reported in Theme 1:

*"The opioid regulation, there is a statute about having the opioids available [now], so there is a legalisation of opioid availability, and even the nurses, are able to prescribe the opioids, which increases the access to opioids." Activist, Africa (P16)*

Empowering nurses to deliver pain relief in circumstances where doctors are not available is a potentially effective strategy for improving access to pain medication. Yet, it is not simply a lack of skills which limit medical professionals' prescribing habits. In many settings, 'fears of opioid' were reported. Most participants appeared to dismiss fears regarding opioid use as an issue of misunderstanding. However, justifiable concerns were identified relating to fears of opioid misuse. One participant described the balance which must be struck between under-availability and over-availability of opioids from a public health perspective:

*"There are basically two public health interests here, one is patients who need opioids for pain management or other medical purposes need to have access to them. And on the other hand, there is the interest that you don't, you want to avoid non-medical, non-supervised use of these substances, because, it creates, it creates another health problem, whether that is drug dependence, or its overdoses" Activist, North America (P16)*

Certainly there are potential health risks associated with long-term use of strong medications as identified above. However, the patient representative offered a different perspective regarding fears of dependence amongst end of life patients:

*"If opioids do cause dependency, who cares? Does it matter? To somebody who is in the last phases of their life, I think it's going to be the last thing on their mind." Public-patient Representative (P11)*

Understanding this quote broadly, is suggestive that even alongside dangers associated with opioids, that ensuring access is paramount – over and above the potential risks. This tension between

emphasising limitations upon the use of opioids and prioritising their facilitation is one which is mirrored at global level. Indeed many national-level barriers to access to palliative care and pain treatment are reinforced by global level policies. On this basis, the following section proceeds to review international and global level factors which influence access to palliative care.

### **Global level influences over access to palliative care**

Considering how factors at global level may have influence over access to palliative care services, the broad perception amongst respondents erred towards understanding the global level as an untapped resource for the further development of palliative care. That is, rather than presenting barriers, that the global level is characterised by a lack of interest in palliative care – as well as a lack of understanding of why it is important. Few participants identified serious barriers at global level. Indeed, when asked ‘what key changes would you like to see at global level to further the development of palliative care?’ many participants responded with issues which would more appropriately be dealt with at national level. However, as has been demonstrated throughout this thesis and will be shown, global level policies have the potential to not only change the healthcare agenda for the global community, but to monitor progress and equip advocates with evidence which they can use to hold their governments responsible to commitments such as the WHA Resolution.

Firstly, however, it is appropriate to reflect participant views which did not recognise a significant role for global level actors in the development of palliative care. For instance, one participant who responded to key questions in writing as well as by interview listed three changes as:

- *“Oral morphine is available in all countries signatories to the UN Conventions*
- *Palliative care courses are incorporated in the undergraduate education of physicians, nurses and pharmacists.*
- *Palliative care services are provided in primary care and community level.” Physician, South America (09)*

Indeed these changes would require national-level action. However, it was established in Chapter Three how the WHO is attempting to further such issues through leadership, formalised in the WHA Resolution. Moreover, it was shown how the regulation of strong medicines by the International Narcotics Control Board was contributing to a restrictive, rather than enabling, regulatory environment. Indeed, signatories to UN conventions on access to essential medicines are not

currently held accountable for failing to ensure access to medicines. However, as INCB regulations *do* permit restricted access to opioids and it is national-policies which specifically preclude this, regulatory barriers do exist most notably at national level. Furthermore, not all participants acknowledged any need for the involvement of global actors in improving access to essential medicines. Speaking of India, one participant stated:

*“I don’t see the global situation affecting us in any way, because of the fact that we grow enough opium” Physician, Asia (P05)*

This suggests that global level regulations are not limiting access and that neither is India reliant upon global trade in order to ensure opioid availability.

Thus, not all participants acknowledged the potential role for global level actors to contribute to the further development of palliative care. However, more prevalently, participants acknowledged the need for increased engagement from global actors in palliative care issues. Yet although few global-level barriers were identified by participants, there was broad frustration that global actors were not doing more to contribute to development. Perceived global *inaction* with regards to palliative care was attributed to a broad lack of awareness amongst global level policymakers which suggests that this national-level barrier is mirrored at international level:

*“I think really the main pushback is really lack of understanding of what palliative care is and also the link of palliative care with end of life care, that is a big pushback.” Activist, Africa (p16)*

This suggests that activists are not currently providing a clear message to global actors. Furthermore, the lack of any globally-collected indicators of palliative care development was seen as a major hindrance to the development of palliative care. Speaking at the cusp of the finalisation of the Sustainable Development Goals (SDGs), there was pessimism regarding the likelihood of a palliative care-relevant indicator being included:

*“We really would like an indicator for palliative care, but that’s not going to happen, I mean palliative care is like I said, is like 1 percent of the population requiring palliative care, we’re not going to get a health indicator.” Physician, Africa (P07)*

Indeed no indicator for palliative care was included in the final SDGs. This must be of serious concern to the palliative care community, due to the importance attributed to an indicator, in terms of both raising awareness of palliative care as well a mechanism with which to hold national governments accountable to their responsibilities as well as for advocacy purposes:

*“Once we have an indicator, we can then go to our Ministry and say, ‘you need to be held accountable to this indicator, so you need this indicator to be part of your Country Operational Plan, then when we go to USAID, we can say, ‘this is part of the Kenyan Operational Plan’, ‘this thing is in the plan, please fund it’”* Activist, Africa (P16)

Yet, in-keeping with the complexity of outcomes associated with palliative care, the most appropriate global measure appeared to focus upon just one element of palliative care; opioid consumption. The consequences of focussing upon just one element of a complex intervention, such as palliative will be reviewed in Theme 4. However, before proceeding to give of an overview of the potential benefits that palliative care may have for a variety of stakeholders as well as the consequences which may occur, where palliative care is absent, it is first important to consider the implications of experts’ varied and at times conflicting, characterizations of the professed ‘global need’ for palliative care.

### **Theme Three: Broad Benefits of Palliative Care and Consequences of its absence**

*“Strongly, I can say it, better palliative care is better society. This is what we’re looking for... to have healthy, better, compassionate societies.”* Physician, Europe (P10)

This theme emerged to reflect the wide reaching benefits which participants suggested that palliative care may offer. Counterfactually, where palliative care is not accessible, it was commonly suggested that there are negative effects, or harms, caused by absence of services. Additionally, understanding just what exactly palliative care offers, helps inform the ‘key message(s)’ of what palliative care advocates should be requesting when engaging with policymakers and funding agencies.

Benefits of palliative care (and counterfactual harms) were revealed for a diverse range of

stakeholders. As such, although all stakeholder groups are inherently linked, benefits and harms are presented by group. Although it is acknowledged that a key tenet of palliative care is to treat patients and families/carers as the unit of care, potential benefits and harms for each group are presented separately.

## Patients

The benefits of palliative care for patients living with serious illness are well documented in terms of reduced symptom burden and improved quality of life and were reported in Chapter Two.<sup>ii</sup> On this basis, though such outcomes were present in discussions, the focus here regards less commonly reported benefits for patients in order to present original findings.

For instance, in spite of historic associations between the introduction of palliative care following a cognitive shift, towards acceptance that not all illness can be cured, evidence emerged in contrary to this viewpoint. Participants revealed that the promotion of person-centred care and quality of life, was not tantamount to an acceptance of shortened lifespan. Indeed, whilst not a goal of palliative care, it emerged that palliative care may in fact *extend* life, a factor which was certainly presented as a ‘benefit’:

*“We actually have some emerging evidence that you have a better chance of survival if you get palliative care than if you don’t, I mean, one study that I did, and a more influential study that was published a couple of years ago on palliative care for non-small cell lung cancer [suggested that] in some cases they may live a little longer, whereas, if you’re in the healthcare system and you’re getting over-aggressively treated, you actually, may shorten someone’s life. We’re talking, a month or two here, not long term survival, but anyway.”*  
Physician, North America (P03)

With improved quality of life and length of life not necessarily in opposition, an additional ‘benefit’ suggested by participants was that effectively delivered palliative care has the potential to reduce the circumstances in which patients may seek to end their lives prematurely due to intolerable suffering. As one participant argued:

*“We often talk about palliative care being the answer to assisted dying, because if we can provide that comfort, that support, that relief of symptoms, spiritual care and all of*

*that...then we would think that a lot of people who would like to end their lives, would change their mind” Nurse, Africa (P06)*

Whilst this benefit was presented anecdotally, another participant described situations where absence and lack of awareness of services may actually lead to far more extreme, negative outcomes, for example:

*‘I’ve heard of current cases and I know cases that patients commit suicide because they do not have access to pain relief” Physician, South America (P09)*

Before proceeding to discuss broader benefits of palliative care beyond those of the patient, it is important to acknowledge that the benefits suggested thus far, have an implicit association with care delivered close to the end of life. Yet, several additional potential benefits for patients emerged in circumstances where palliative care was delivered much earlier in the course of illness. For instance, one participant from Africa spoke of how people through early introduction of effective symptom management, may experience fewer restrictions on their capacity to maintain their usual social functions:

*“Some of these people are able to go back to productive work, so it’s helping them make sure that these people stay as healthy, as pain free and as symptom free as possible, so that they can continue with their every day job. We have people who have gone back to their teaching job, or you know, whatever jobs they do, you know, driving jobs, because they are now, now their pain is controlled and their symptoms are well managed.” Activist, Africa (P16)*

Benefits such as ‘returning to work’ are implicitly associated with palliative care at an early stage in the course of illness. Certainly it seems unlikely that patients closer to the end of their lives would have the likelihood to return to employment. Although it may be suggested that such benefits may be extended to improvement of quality of life through maintenance of usual function for as long as is possible. Understanding benefits in this manner reveals a key tension within the field of palliative care, whereby some participants chose to emphasise improved quality of life through the early introduction of palliative care, whilst others focussed upon issues regarding the end of life, a point which will be expanded upon in subsequent sections.

Before discussing the relationship of varied benefits for stakeholders beyond the recipients of care,

it is first appropriate to provide an overview of the suggested benefits for other groups. Here follows the suggested benefits for the broader targeted unit of care: families and informal carers.

### **Families and Informal carers**

It is reasonable to suggest that all of the professed benefits to patients of palliative interventions are shared by their broader support system: families and carers. That is, that what is beneficial to people suffering illness extends to include those who care for them. Additionally, participants reported upon benefits which families and carers may receive through their incorporation within palliative care services which may be considered of *specific* benefit to them. The starting point here is to acknowledge the prevalence of such support systems within societies. One participant described family caregivers as “the largest workforce in the healthcare system [Physician, North America (P13)]”. More globally, another described how, when families are included in the statistics of disease prevalence alongside patients, the estimated need for palliative care rises from 54.5 to “More than 100 million [Physician, North America (P03)]”.

In order to understand the significance of palliative interventions for caregivers, it is important to acknowledge just how seriously the act of caring for a loved one with an illness can affect caregivers. One participant discussed the trauma that is experienced, indicating that:

*“There are studies of mortality and morbidity of caregivers, where there has been no hospital and palliative care, which show that families that don’t get good hospice and palliative care are much more traumatised and in fact have PTSD [post-traumatic stress disorder]-type symptoms” Activist, North America (P01)*

Equating caregiving with PTSD, an illness commonly associated with experience of warfare, underlines just how seriously caregivers’ lives can be impacted through experiences of caregiving. However, this is not to suggest universally negative experiences of caregiving through which people may have a wide range of positive experiences. Yet, potentially negative experiences of caregivers who are not receiving palliative care only serves to underline the need for families and caregivers to be supported in challenging circumstances. In this regard, it is of surprise, that when describing the global need for palliative care, that such conversations did not include specific reference to caregivers’ specific needs.

Aside from discussions of the emotional and physical impact of caring for somebody with a serious

illness, many participants alluded to how appropriate cessation of active treatments in favour of palliative care may have financial benefits for families. In circumstances where people pay 'out-of-pocket' for care, it was revealed, how aside from the physical suffering which futile treatments cause for patients, they also create a heavy financial burden upon families. Reporting upon a study which reported upon the financial impact of illness upon families, one participant described:

*“Two unexpected outcomes ... one of which was about 30% of families, even if they are well insured go bankrupt, and in about 25% of families, somebody needs to stop their career to become a caregiver, and loses their future career. Those are pretty profound effects [which were attributed to] spending more time in intensive care units, they were having more admissions, more transitions” [Physician, North America P13]*

Whilst the negative effects which such medical care may inflict upon patients, the consequences of heavy financial outlay may be felt most keenly by families. It is also worth noting the negative effects of 'losing a future career' both financially, as well as upon quality of life if a person cannot perform their usual duties. The suggestion here is that if palliative care is introduced effectively, that not only is more appropriate care given, but negative financial factors associated with costly (and ultimately futile) curative treatments are avoided. Thus, increased financial burdens upon families caused by out of pocket expenditure upon futile care are removed – to the benefit of both the patient and the family. However, it should be acknowledged that some studies have shown that palliative care can be associated with a high amount of out of pocket expenditure for families.<sup>iii</sup> In this regard, it is not known whether palliative care represents an overall reduction in overall expenditure for families, a circumstance which is likely to be highly context specific.

Yet, perhaps the benefit emphasised most strongly by participants, though not related to 'inappropriate' treatments, lies in how the families experience the illness suffered by a loved one. Examples emerged from around the world referring to how peoples' experience of illness of a family member has implications for if and when that person may suffer illness themselves:

*“If you're nervous and then frightened, as you enter your own illness experience, you're probably not going to do very well, and it's going to be a very frightening experience. If you realise from the beginning, because of a loved one's story, that you can have great palliative care and hospice care. Gosh, it makes it very different.” Physician, North America (P13)*

Thus positive experiences of illness and death through effectively delivered palliative care may lead both to benefits beyond improved health outcomes and reduced financial burden. Indeed it was a common narrative, that peoples' attitudes towards illness and death may be improved through facilitative experiences through a realization that death "can really go quite well" [*Physician, North America (P13)*].

Finally, the PPI Representative within the sample concurred, that such support prior to bereavement, was important for positive experiences of death:

*"A good death, well, when you your family and your community are prepared for it, where there's no suffering, and when you die in your sleep I suppose. Bit over ideal that isn't it?"*  
*PPI Representative, Europe (P15)*

Considering the potential broad benefits of interventions for families and caregivers, adds a new perspective upon the value proposition that palliative care has to offer. Furthermore, as the quote alludes to, patients, their families and caregivers, exist within broader social systems. With this in mind, the following section proceeds to discuss how potential benefits from palliative care interventions, may be felt within broader communities and indeed societies.

### **Communities and societies**

Whilst communities and societies are not the targets for palliative care interventions, many participants professed how the act of caring for people living with serious illnesses and their care systems has benefits much wider than simply for the unit of care. Such claims centred around how through increased acceptance of vulnerable people and improved attitudes to illness and death, hold the potential to increase societal and community resilience. In this regard, one participant commented palliative care can lead to:

*"Societies where the frail, the poor, the marginalised, can be included. Then, in some way palliative care is secular relation to have better societies. Is not only about the care of the terminally ill patient it's about better societies." Physician, Europe (P10).*

Such claims are somewhat intangible. It is therefore, appropriate to consider the type of community and societal level problems which palliative care may be able to alleviate. Predominantly, such

discussions regarded societal attitudes to illness and death. Such narratives are related to issues previously addressed regarding how people living with serious illnesses may be considered a 'marginalised group'. Specifically, stigmatization towards people living with illnesses such as HIV/AIDS were said to be treated with suspicion by the broader community. Speaking of communities attitudes at the onset of the HIV/AIDS crisis in Africa towards patients at a recently established hospice, one participant reported that people:

*"Wouldn't support the adults we were caring for, because, 'what have they done? They deserved it'" Nurse, Africa (P06)*

Evidently such perceptions of people living with illness are not conducive to community cohesion. That is, if people are isolated in this manner, then communities become segregated. More broadly if attitudes such as 'they deserved it' pervade, then such circumstances do not provide fertile ground for public support for palliative care services. In spite of such barriers, one participant reports upon how attitudes have been challenged by reaching out to communities and recruiting community members as volunteers:

*"I think what we have seen is when we have included communities as volunteers, as people who are supporting each other, you find first of all, you find the stigma of illness is reduced, because we are talking about it openly, people can see the benefits of being involved, now this brings people together, so people are not afraid to say 'oh, my neighbour is having a problem can we help?', so reaching out, knowing each other, knowing where you can get help, that has really brought villages together" Activist, Africa (P16)*

Such processes of inclusion are supported by studies regarding 'health promoting palliative care'<sup>lxvi</sup> which will be considered in the discussion section, however would appear to occur in diverse ways in different world regions. For instance, one North American participant made the suggestion that palliative care challenged not only attitudes to illness, but held the potential to improve race relations in the United States. Informed by a historic circumstance where African Americans are less likely to access palliative care services, it was suggested that when they *do*, that attitudes are challenged:

*"When [African Americans] do come into hospice then there's a lot of fear and mistrust, but again, when you bring the family unit into it, and then they see that they're cared for and*

*helped in this really life-affirming way, that changes the dynamic and it changes the conversation around race and...it changes people' experience so that they can then get to another level... If you think counterfactually, then it's like, well, if that didn't happen, then they wouldn't have that resilience and they wouldn't have that perspective and they might still hate white people" Activist, North America (P02)*

Evidently there is symbiosis between ideas regarding involvement of the community in providing palliative care as a mutually beneficial relationship. Furthermore, it was suggested that through the adoption of open conversations and involvement of stakeholders beyond healthcare professionals in the provision of care and patients' lives, that stigma towards conversations about death were improved:

*"When I was in the hospice, and the patient was unwell, and probably at the end of life, the rest of the patients were aware that this was happening, and they'd come into the room and they would help, provide, or giving water to the patient or helping them to stand up, so they were quite involved in, not patient care, but I would say it's much more important than patient care, it's patient accompaniment... So it was a much more, or I would say, less 'taboo' also and much more community-approach than what you see [in North America]." Physician, South America (P09)*

Additionally, non-institutional care, that is, home care, was also suggested to be a facilitator of community cohesion:

*"In most African countries, palliative care is offered at home, within the community and at home. And that creates opportunities for bonding and coming together." Activist, Africa (P16)*

In addition to benefits of palliative care felt at the community, it was suggested by a North American participant, that communities had an important part to playing in the provision of care. Moreover, it was claimed that the failure to utilise community resources to provide palliative care threatens the very sustainability of health systems:

*"The reality is that we need to mobilise the community to support these people... As we think about the Kerala [community-led] model, it's quite interesting, it could be adapted, we don't have the resources in Western Europe and North America to continue giving the care the way*

*we do it, we just don't have the resources, and with the dependency ratio changing, and becoming actually quite serious in several countries, we're going to have to have a different model because we're not going to be able to afford it, people won't have the money."*

*Physician, North America (P13)*

The suggestion that palliative care holds potential benefits for health systems will be explored further in the following section. Firstly, however, whilst increased cohesion may be felt at community-level, several participants suggested that improved community relations translated to the societal level. An idea supported by the PPI representative who makes additional links between different stakeholders identified within the theme:

*"Whoever is caring for someone who is having palliative care, their quality of life will improve as well. So, the ripples spread out to the whole of society, you know, one suffering person can bring a lot of misery and unhappiness to the family, and possibly even to the neighbourhood"*

*PPI Representative, Europe, (P11)*

It is appropriate to say, that as the professed 'benefits' of palliative care move further and further away from the intervention itself, that they become less tangible. Concepts such as 'community cohesion' are difficult to measure, however this suggestion is by studies which have shown that a 'health promotion' approach in palliative care is consistent with greater community engagement with caregiving and recognition of end of life issues.<sup>lxvi</sup> Moreover, the idea of 'ripples spreading out to the whole of society' as suggested by the PPI representative, was shared by other participants, one of whom went further, linking community benefits to global issues:

*"[Palliative care] delivers better outcomes for families, communities, states and regions and eventually the world than not having palliative care...It builds the kind of resilience that allows families, communities and individuals, we'll just stay with those three, to address, other really critical problems, such as climate change, crime, migration, development, whatever you want to call it. Because, to me palliative care advances the emotional intelligence of society."* Activist, North America (P02)

No direct causality is implied between individual palliative care interventions and issues such as climate change. Nevertheless, the idea of improvement in the 'emotional intelligence' of societies is conceivable in terms of some of the negative attitudes and practices towards illness and death identified within this theme. With this in mind, it is troubling that broadly, societies appear to be

acceptant of existing medical practice and its 'search for a cure'. That is, that whilst palliative care remains so globally underdeveloped, that societies are unaware of the potential benefits of palliative care which have been suggested and are therefore not receiving them. A strong view emerged from Europe in this regard:

*"Probably from the sociological point of view or the political point of view, it's interesting to look at our society as mad, it's mad, it's treating patients with chemotherapy, thousands of euros in the two weeks of life, what is that? That society, probably is mad, is mad, why don't you explain to that patient at the end of life who is not receiving any benefit from this treatment, he will still be in the hospital, he will not recover from this chemotherapy, you know, it's in some way, why we need palliative care, because we don't have money to pay health." Physician, Europe, (P10)*

As hinted in all sections within this theme, the relationships between the potential benefits to different groups are complex. This issue will be addressed following the final element of this theme, by turning to attention to how palliative care can benefit health systems and health workers – as suggested by the participant in terms of sustainability.

### **Health systems and health workers**

Arguments for how further rollout of palliative care services may hold benefits for health systems followed three main strands. They centred around: 1) how better quality care as opposed to overly aggressive and expensive treatments may provide cost-savings to health systems whilst almost being more appropriate for patients, 2) how a public health approach, increases the skillsets of medical workers results in higher quality medical staff and 3) more resilient staff, better able to deal with the emotional burden which may come for caring with people with serious illness up until death and a consequent reduction in staff burnout.

Health care professionals dealing with seriously ill people up to and including the death of the patient, face similar emotional and psychological challenges to those of families and informal carers. This point was made by several palliative care physicians with a great deal of experiences in such circumstances:

*“Every single person helping a person with an advanced illness, so whether it’s the family, or friends, or whether it’s the healthcare workers, they’re all watching their own future!”*

*Physician, North America (P13)*

Such experiences were echoed in an Africa setting:

*“[If] the patient has a comfortable death, that is not distressed because that improves bereavement outcomes and improves people’s future mental health. If they’ve had a good experience around a death compared to a really, bad, and upsetting experience around the death.” Physician, Africa (P07)*

This point echoes one of Cicely Saunders’ fundamental principles of palliative care, that ‘how people die lives in the memory of those who live on’, and the significance of a positive experience for health professionals in such circumstances should not be underestimated in terms of their own bereavement experience and mental health.<sup>liii</sup> This is significant also for health systems, as positive experiences in this regard “reduces the risks of frustration and burn out [Physician, South America (P15)”, a benefit which can be extrapolated to a potential reduction in absences from work due to such factors. Indeed, running counter to narratives of death as ‘failure’, it was reported how facilitating positive experiences towards the end of life can itself increase job satisfaction of health workers:

*“As a healthcare professional, when you’re working with that patient, if you can see that you’re relieving the pain, you’re dealing with the existential suffering of that adult or child, it gives you a feeling of success, you feel better about yourself, about your interventions.”*

*Nurse, Africa (P06)*

Furthermore, arguments presented previously, that palliative care skills should be a fundamental part of undergraduate medical training, was said to have impacts within the health in all clinical settings:

*“The essence of the health professionals is the essence of palliative care, in other words, the essence of the medicine, the essence of the health professionals, are in palliative care, working with palliative care will mean better professionals, better medicine also to attend the patient, this is another reason to have palliative care.” Physician, Europe (P10)*

Once more this revives questions regarding how the current medical approach of focus upon illness rather than upon the patient may be changed. It also suggests increased professional competence, which must benefit health systems, health workers as well as patients.

In this regard, medical professionals' decisions regarding cessation of futile treatments in favour of a palliative care approach may be linked to both patient-benefits as well as financial benefits for health systems. The final quote of the previous section painted health systems which treat patients with expensive, ineffective chemotherapy at the end of life as irrational and raises questions both about the appropriateness and sustainability of existing medical practice. This was a commonly held view amongst participants and indeed similar arguments were made for both high and low resource settings. Reporting on North America with the context of the costs of delivering palliative care towards the end of life as opposed to continuation of aggressive, futile treatment:

*"We showed that for every patient seen by the consult service at our largest hospital, we saved a thousand dollars per patient admission to the hospital. And at the smaller hospital, which is 340/50 beds, we saved \$500 for every patient seen."* Physician, North America (P13)

These are significant savings and links to a previous point made by the same participant regarding the need for communities to be mobilised to be more active in supporting informal caregivers in delivering palliative care, not simply as a preference, but as a financial *necessity*. Thus the empowerment of informal carers may be linked with decreased (expensive) hospitalisations as well as more appropriate care. This suggestion was made for both low and high resource settings, as represented by the following quote, which relates firstly to the Indian setting, and then to 'Western' settings:

*"How do we create a whole process to reach out, these family caregivers, they don't have any training in how to do care, we don't give them any education, many of them are actually illiterate, and we hand them these fancy brochures, the hospital discharges them and sends them home, and then they come back and we wonder why. We don't have the resources in Western Europe and North America to continue giving the care the way we do it, we just don't have the resources, and with the dependency ratio changing, and becoming actually quite serious in several countries, we're going to have to have a different model because*

*we're not going to be able to afford it, people won't have the money" Physician, North America (P13).*

On this basis it may be stated that all international health systems face challenges relating to their sustainability which may be reduced through further provision of palliative care. Echoing a finding from the systematic review in Chapter Five, is the suggestion that the potential for palliative care to save health systems money, is undermined by the lack of an evidence-base to demonstrate this:

*"Palliative care actually saves costs to the healthcare systems, by providing care which is actually cheaper and less expensive when it's at home and then preventing that patient occupying a hospital bed and using the emergency resources and hospitals and third-care level facilities, which are quite expensive. That kind of community based, home care based, approach to palliative care does, you know, save a lot of money, but we need more studies and we need more data." Physician, South America (P09)*

Such findings add weight to claims of advocates that a public health approach be taken to development. In this regard, governmental funding for palliative care may be represented as an investment in people and services, whereby financial input will ultimately lead to overall financial savings.

However, in spite of broad support from all participants for a public health approach to be taken to palliative care development, many services continue to operate outside of the formal health system. Moreover, questions emerged during interview regarding the feasibility of integrating all elements of palliative care into mainstream health systems. Therefore, the following theme emerged to answer questions regarding whether any single aspect of palliative care should be prioritised over any other in order to make developmental progress as well as the relevance of public health approaches to private healthcare systems.

#### **Theme Four: Prioritisation Within Health Systems and Organization of Services**

To some extent traditional definitions of 'health systems' do not accurately capture the diverse range of formal and informal organizations which provide palliative care around the world. The

global development of palliative care has seen services develop patchily, both within and between nations. Similarly, development has been characterised by diversity, with models of palliative care provided formally by health systems, but perhaps more commonly, by charitable organizations, civil society led services and private institutions and services which operate outside of nationally funded health systems. This diversity raises real questions regarding the sustainability of services, whereby, funding streams are dependent upon bilateral relationships and services are often not underwritten by nation states.

On this basis, a great deal of discussion regarded the feasibility of more fully integrating palliative care into both public and private health systems. Central to such discussions was a shared view amongst participants that palliative care should be integrated into all international health systems, using a public health approach, arguments which were strengthened based upon the benefits of palliative care for different stakeholders identified above.

Given that palliative care continues to operate outside of formal health settings in many world settings and the shared challenges to the sustainability to *all* health systems, there is an urgent need for both new resources for palliative care both to fund and deliver services. This may be achieved either through gaining access to new sources of finance and labour, or by a reallocation of existing resources. The following section therefore reviews participants' views on the extent to which a health systems approach to palliative care development can be encouraged, along with how the integration of palliative care should be funded.

### **Health systems approach to development**

As identified in the previous theme, experts within the sample suggested that palliative care offered benefits to health systems including more appropriate care, increased competence of health professionals as well as cost savings. Additional to attitudinal barriers to palliative care development, questions regarding the feasibility of further integrating palliative care into formal health systems have emerged. Both global and national level healthcare governance systems are characterised by competing claims for limited resources. This is particularly true, for developmental health systems, which have not evolved to incorporate high quality services at primary, secondary and tertiary levels. Within such systems, activists face additional challenges regarding the integration of palliative care into health systems. Yet, even highly developed health systems face challenges to their sustainability, from increasing populations and shifts in the age dependency ratios, which have seen fewer people

paying into health systems which are attempting to meet the challenges of increased need and usage.

With regards to how to ensure a sustainable approach to palliative care development, there was broad agreement amongst participants that national governments should adhere to WHO guidance regarding a public health approach to palliative care development. This guidance centres around 4-key pillars:

*“The concept of palliative care from the World Health Organization, the pillars, the four pillars of palliative care. Policy, education, implementation and drug availability... if you think about that public health approach to palliative care, thinking about those our pillars. The WHO says that for palliative care to be accessible to all those that need it, those four pillars have to come into play” Activist, Africa (P16)*

There was broad acceptance that nations should follow such an approach. Moreover, few participants considered that government may need financing outside of their existing budgets and placed the financial burden for the integration of palliative care directly upon nations.

*“The funding for palliative care needs to come mainly from national governments. At least it depends, in some countries its healthcare insurance, in other countries it’s the government directly who finances healthcare and that’s the direction it needs to go in I feel. So, palliative care needs to be financed in exactly the same way as other healthcare interventions are financed at the moment. For me, that’s the ultimate objective.” Pharmacist, Europe, (P01)*

The point regarding healthcare insurance will be addressed in due course. However, the above quote regarding how palliative care ‘should be financed in exactly the same was as other healthcare interventions’, disregards the fact that in many world settings, financing comes from charities, philanthropists and global funders. For instance in Uganda where it is professed has achieved full integration of palliative care into the health system, it was reported that:

*“They [are] really working, even now, they do work with money from donors, with very limited support from the government.” Activist, Africa (P16)*

What is more, despite agreement that palliative care should be incorporated into national health

systems alongside all other aspects of medicine, there was recognition that ‘developmental’ health systems were likely to focus first upon the provision of primary care services:

*“If you think about it, developmentally in a country, if you have limited resources, and you’ve got a whole group of people dying from something like HIV, you want to do palliative care... where do you put your focus? Do you put it on palliative care, or do you put it on curing people? If you don’t think it’s important, people put it on curing people, or trying to save them, what people haven’t understood is that palliative care is actually very inexpensive to implement it, and you can actually do both. And what even the palliative care community has not talked about, is how palliative care can be involved with identification of other people at risk.” Physician, North America (P13)*

This links back to a previous quote regarding the role of palliative care in the whole continuum of care, including health promotion and prevention. Yet, in spite of this emphasis upon feasibility, the quote also displays pragmatism, based upon an understanding that this link is to some extent unexplored, and certainly does not represent the conventional wisdom amongst health policymakers. In this regard, there was implicit acknowledgement that donor-financing may be required in order to accelerate development.

Yet, in order to access such funding responsibility was still placed upon national governments to have national strategies for palliative care in order to align donor objectives with those of national policy. This approach is consistent with donor commitment to alignment with national objectives identified in Chapter Three. The potential for palliative care to benefit from global level funding streams is considered in Theme Five. However, it should be noted that rather than a focus by participants upon engaging global funders, more common was the view that it is the responsibility of national governments to fund the integration of palliative care.

Participants suggested that governments did not necessarily need new sources of finance, but identified the possibility for a reallocation of existing health resources to further palliative care development. Suggestions for how a reallocation of human resources within health systems held potential to advance the interests of both palliative care and health systems arose from two distinct premises. The first, related to how the non-treatment of patient symptoms within health systems increases the manpower required to treat that patient as reported by one participant:

*“If there is a category of patients who are in pain, who are not treated for the pain now and need a lot of support almost continuously, healthcare systems or economies would save a lot of money if they treat the patients for their pain. And that can be either that a nurse can do something else, or you need less nurses or that a relative taking care of a person at home can go back to work or do other things” Pharmacist, Europe (P01)*

This strand of argument relates additionally, to how better and more appropriate use of resources may contribute to both more appropriate care, as well as the economic sustainability of health systems. Secondly, the quote is may be understood as being supportive of maximising use of existing human resources through the empowerment of nurses to prescribe as addressed previously. In this regard, it appears that there is an argument to be made, that if nurses were able to treat pain, this may not add undue work to their caseload and may in fact decrease workload, based upon the suggestion that patients who are not treated for their pain require more continuous attention. Conversely, it was suggested, that the implementation of palliative care as opposed to continuation of futile treatments in and of itself, raises the resources required to deliver palliative care. Reporting from Europe, one participant described how this circumstance occurred in practice when a palliative physician requested the costs of chemotherapy for people who did not live for more than two weeks post-treatment:

*With this data, he went back to the boss of the hospital and explained, ‘one palliative care physician is 30,000 euros per year, you are spending this with 30 of the patients you are treating at the very end of life with chemotherapy, but you are not treating in this hospital, 30 patients, you are treating in this hospital 300 patients with chemotherapy in the last two weeks of life. With the money that I can save, you can contract 10 palliative care physicians.’*  
*Physician, Europe (P10)*

Ideas regarding how resources within healthcare systems may be used more appropriately, both by redistribution and by empowerment offer clear objectives for palliative care advocates and are consistent with a public health approach to development. However, public health *systems* represent only a proportion of international health care systems. In this regard, it was appropriate to consider the relationship between palliative care, private health care systems and other private healthcare actors.

### **Palliative care and private hospitals**

As referred to previously, in many settings, national governments are not the primary source of healthcare financing in many world settings and there has been a proliferation of private health systems worldwide.<sup>liv</sup> Three key industries were identified as being relevant to palliative care within the private sector; health insurers, pharmaceutical companies and private hospitals. There are inherent complexities within each of these industries in terms of their interests, however they are united by a shared 'bottom 'line' to make money. This has significant consequences for palliative care activists in terms of how activists present the feasibility of integrating palliative care into private systems.

Privately funded health systems, differ in their structural organization, however, commonly, people either pay for healthcare at the point of use, or pay routinely for medical health insurance for care which is free at the point of use. Each of these models presents both obstacles and opportunities for advocates to make arguments for the integration of palliative care into such systems. In this regard, whilst economic arguments for palliative care have emphasised 'cost-reduction' to health systems, this argument may not resonate with private healthcare providers. When asked how economic arguments may be made to private providers one participant responded:

*"That's a good question, particularly in our setting [USA], where it means reduced revenue. Well it depends on the funding model doesn't it? So if the funding model is 'fee for service', like in Ohio, 80% of our business is fee for service, there's absolutely nothing attractive about saving revenue. What there is attraction is, saving expenses, because if I can have the same revenue and reduce expenses, then the hospital is very interested."* Physician, North America (P13)

This distinction is significant as on the one hand, if the provision of palliative care within private hospitals is likely to reduce their profitability, then this can be considered a real barrier to the integration of services into such systems. Conversely, if private hospitals can be engaged using arguments regarding how providing more appropriate care may cut expenditure, then this may be considered a real opportunity for the integration of palliative care into private systems.

However, real concerns emerged regarding the private sector in terms of the vested-interests that private industries have in the current technical approach to healthcare. That is, that the very futile, inappropriate and expensive treatments towards the end of life which palliative care advocates

oppose, are incredibly profitable to the private medical industry. Commenting upon this dynamic the PPI Representative stated:

*“[Patients] will go through anything to get the cure, they will have massive operations, they will have repeated surgeries, they will take any drugs and of course they’re pushed upon them, by I suppose you could say, predatory medical profession. I’ve heard a quote that ‘if you can’t get fifty thousand dollars out of a cancer patient, then there’s something wrong with your work’.” PPI Representative, Europe (P11)*

This suggestion is of real concern, particularly when another participant described how medical professionals may be both put under pressure within private hospitals to promote expensive treatments to patients and indeed have a vested-interest in doing so:

*“Private doctors are driven, by saying ‘yes, come back for fourth-line chemo’, even if it’s not working, because I’m going to get paid more for doing the chemo” Physician, Africa (P07)*

Yet, the one private-sector physician included in the study, urged caution when characterising the private sector as being a barrier to palliative care when asked about such circumstances:

*“The regimen that we follow is, ‘...I have full dedication to the hospital, then I receive my money, my amount of money, with independence of the amount of the patients I am treating each month, then it that way, I don’t feel the pressure of treating patients in one way or another way” Physician, Europe (P10)*

Furthermore, the same participant described how working within a private hospital, facing fewer pressures of demand, allowed freedom for innovation. Accordingly it was described how private systems with their additional resources for research and development, may be able to offer leadership through the creating of appropriate models of care which the public sector may be able to emulate:

*“I am privileged physician in that way, for me, I can develop things in an easy way, in an easier way, than other physicians in the public health system. Why? Because my hospital is a small hospital, with less patients, with less pressure, with less stress... And in that way I can develop better a model of palliative care, a model, and from that model I can influence in the*

*health system. This is one way. Private system could be a better system to design, to develop models for the public health system.” Physician, Europe (P10)*

Thus, conceptualising the relationship between palliative care and the private sector is extremely complicated and no single narrative is suitable for addressing this complexity. Yet, this positivity regarding how public and private systems may operate well in tandem was not shared amongst participants. Tensions were revealed in other settings where public and private health models exist alongside one another. Referring to this in the context of Uganda, one participant reported:

*“In terms of other private hospitals, private doctors, it becomes very tricky, because one of the things you want to be careful of, is to encourage them to include palliative care as their role, but then the problem is, you don’t want to refer patients to a private entity if you are not sure they are going to be able to pay, because then you are creating businesses for private entities with patients who you are not sure if they are going to be able to pay, so you have to be very careful about that” Activist, Africa (P16)*

Questions relating to pay-for-use services raise real concerns in terms of equity of access to palliative care. Within private systems, governments remain obliged to ensure that access is not determined by social status. Yet, as independent organizations, private health services are not subject to the same influence of government policies and regulations as national health services which may limit the ability of governments to act in this regard and there are known inequalities of access within private health systems.<sup>lv</sup>

The predominant attitude of participants was to view the private sector with suspicion. With private systems so prevalent internationally however, it of concern that when speaking about ‘health systems’, that there was an underlying assumption that this referred to public health systems. Few ideas were presented regarding the different approaches which may be required in order to engage with privately run health systems in order to meet patient need with one participant commenting:

*“Aside from the pharmaceutical industry, I’m not sure that the private sector is that important” Pharmacist, Europe (P01)*

Engagement with pharmaceutical companies is of course important in terms of ensuring drug availability – one of the 4-pillars of a public health approach. What then is the relationship between

palliative care and the pharmaceutical industry?

### **Palliative care and the pharmaceutical industry**

The overriding view which emerged from participants was that due to the low cost of generic medicines such as oral morphine, that pharmaceutical companies held little interest in palliative care:

*“I don’t think they have any interest in palliative care. Pharmaceutical companies don’t have much interest in us... because they don’t make any money from morphine and opioids are our...50% of all drugs we give patients are analgesics, and particularly opioids, and they’re so cheap that the drug companies can’t make a profit on it so they’re not really interested in selling it” Physician, North America (P03)*

Of further concern, some participants described how pharmaceutical influence could be exercised more damagingly. It has been noted previously, how physicians, funded by pharmaceutical companies have spread negative lessons, regarding the promotion of expensive alternatives to generic medicines in low-resource settings. With private companies fundamentally organised to be profitable, the vested-interests of the pharmaceutical industry in existing medical practice should not be underestimated. Referring to how private interests may be affected should the culture of medicine become more aligned with palliative care, one participant commented:

*“A lot of sectors are going to lose quite a bit of profit because the private industry profits from people being kept on machines and on quote/unquote drugs, medicines, until the last breath, it’s very profitable.” Activist, North America (P02)*

Some suggestions did emerge regarding how palliative care may be able to engage better with pharmaceutical industries. Firstly, it was noted how the power of the pharmaceutical industry can assist by promoting enabling regulations which enable better access to treatments:

*“Sometimes, the kind of interests, converge, so for example, in Mexico and actually in India it was the same, you have pharmaceutical suppliers of opioid analgesics, that realise that there is a huge market, out there that is untapped because so few physicians are able to prescribe the medications because of regulatory restrictions, right?... So, you know, in that kind of situation, the pharmaceutical industry can be pushing alongside palliative care advocates for*

*changes to regulations” Activist, North America (P12)*

Secondly, there was some evidence of positive engagement with pharmaceutical companies in terms of promoting ideas relating to corporate social responsibility. One participant referred to an undertaking whereby lobbyists encouraged pharma companies to contribute towards medical training in pain management with some success:

*“We actually generated about 300,000 dollars from American pharmaceuticals to really support training of doctors across Africa.” Activist, Africa (P16)*

Such examples were, however, atypical. Even in circumstances where ‘interests converge’ this does not negate the truism that ultimately, the term ‘private interests’ refers to profits. Therefore in spite of the example noted above, predominantly, the broad view was that pharma companies acted only in their own interests and promoted only expensive medicines which again raises concerns regarding equity of access.

### **Palliative care and health insurance companies**

A potentially more fruitful strategy for engagement with the private sector emerged in relation to health insurance companies, in circumstances where patient and company interests coalesce through reduced time spent in hospital. In situations where health insurance is paid in order to ensure that medical care is free at the point of use, there may be real opportunities for palliative care to engage with health insurers as reduced time in hospital through more appropriate care, benefits patients and reduced costs to insurance companies as one participant explains:

*“In the healthcare industry, the private healthcare, the argument is coming across, is that if you can discharge people from hospital sooner, then as a health insurer you have less pay out, and if you’re not doing the futile care, or having people in ICU for days and days and days, or months and months and months, which is inappropriate care, then you’re also doing cost saving. So they, they’re driven by the health, the cost argument...” Physician, Africa (P07)*

Yet, a key challenge to the palliative care community emerges here, in terms of the *specific* interventions which health insurers should be covering. That is, just what does it mean to have a complex intervention such as palliative care, ‘covered by medical insurance’? This means that there

is a need for clear articulation regarding what health insurers are being asked to cover as one participant explained:

*“I think that with the insurance companies... think about including palliative care in their agendas or in the coverage plans, is this concept of holistic care, because when they want to cost it, they want to know how much it’s going to cost them. And so they don’t know if it’s going to be 3 visits by the doctor or 30 visits by the doctor, or is it going to be a nurse and a doctor, or a nurse, a chaplain and you know, 3 visits by a psychologist or a social worker. So I think that that’s one of the challenges that they face.” Physician, South America (P09)*

This circumstance raises challenges to the palliative care community. Just what is meant by ‘access to palliative care’, what does this consist of and indeed, as a complex intervention, must all elements be present for patients to be said to be ‘receiving palliative care’? Indeed, if the palliative care community is unable to determine what may be considered an adequate ‘coverage plan’, how can health insurance companies be expected to do so?

Moreover, whilst participants expressed great optimism that palliative care would be included in what were at the time the forthcoming Sustainable Development Goals, as part of Universal Health Coverage (UHC), any such inclusion poses the same challenge to the palliative care community:

*“The Universal Health Coverage movement and what we are all aiming for, you know, there’s a global movement for UHC, so one of the things how we can get palliative care as a component of the Universal Health Coverage, they will also... want to know what is the minimum package that Universal Health Coverage needs to cover?” Physician, South America (P09)*

If we conceive of palliative care as being an inherent part of UHC, this increases the need for clear definitions of what access to ‘palliative care’ means in different settings. Furthermore, although palliative care is a complex intervention, comprising service delivery by diverse stakeholders, considerations of what constitutes a ‘minimal package’ of palliative care, also led to further problematisation, in terms of ‘what are the most important elements of palliative care’? That is, if a ‘maximum package’ remains out of reach, then what would be the ‘key asks’ of the palliative care community, which services policymakers should focus upon meeting? We turn to this now.

## Prioritisation between elements of palliative care

When speaking about prioritisation within developmental health systems, as described above, one participant inferred the need for pragmatic decisions to be made. That is to say, for instance, that it is rational to focus upon increasing life expectancy through interventions such as vaccinations, within contexts where life expectancy is particularly low. In the same sense, the question was put to participants in terms of palliative care, ‘if it is not feasible to roll-out all elements of palliative care at the same time, then what should come first?’

It is important to acknowledge before proceeding, that it runs counter to the very definition of palliative care as a multi-faceted discipline, to consider its potential divisibility into separate elements. However, within a context of resource-scarcity, considering potential ways in which ‘palliative care’ might make policy gains seems appropriate. However, this suggestion did not meet with unanimous agreement amongst participants. For instance, when asked about the potential divisibility of different elements of palliative care, one participant responded:

*“We need to make sure we don’t lose sight of the fact that palliative care is holistic care and Cicely Saunders’ total care for total pain... Because that’s what palliative care is, bringing the heart and the compassion and the attitudes and the caring of the healthcare worker, whether they’re the social workers, the spiritual counsellor, or the doctor or the volunteer carer and it’s more...that attitude, that attitude of caring that is the intervention of palliative care. So when you say ‘does it have to be all at once’, it really should be.” Physician, Africa (P07)*

Although this participant was certainly not alone in regarding palliative care as non-divisible, other participants diverged from this view. Especially in terms of strategies for advocacy, other participants saw real value in advancing arguments focussed upon specific elements of palliative care. Referring to the work of their organization, one participant reported:

*“In our research and advocacy we’ve prioritized treatment of pain because it’s often the most pressing issue for patient and family” Activist, North America (P12)*

Focussing upon pain as the ‘most pressing’ issue for palliative care was also deemed appropriate to the PPI Representative, although this view was presented with some qualification:

*“Psychological help, social help, I think those are very nice things to have, so I guess if you’re going to try and save money, I think that pain relief is it... [Though] I think we’re very lucky in this country [UK] to be even thinking of adopting such a holistic and rounded approach to the whole thing, and we should treasure that, not let it go.” PPI Representative, Europe, (P11)*

In this regard, it may be suggested that whilst there are potential prioritisations to be made within palliative care, that these are only relative and that all elements are perceived to be important. However, some participants did not err from the views supporting the idea that ‘everything should come at once:

*“It needs to be the whole package. Because if you’re just doing pain management, you’re not doing palliative care, if you don’t have the others, you’re not giving palliative care, we need to realise that palliative care is a package, it’s never, you don’t just do emotional care, you don’t just do spiritual care, you don’t just do clinical care, it’s the package.” Nurse, Africa (P06)*

However not all participants viewed palliative care development in such terms. Whilst not challenging the philosophy of palliative care as a holistic intervention by sub-dividing it into elements one participant suggested:

*“I think some of the challenges we have had ourselves, as palliative care, is our, our unwillingness if I can put it like that, to put palliative care into different components, which are sellable to different players. Sometimes we always need to say, ‘we want people to take the whole thing’. And sometimes maybe we just need to promote pain, pain management, and just promote that. Sometimes maybe we need to promote just psychosocial support, and because that is what resonates with the person we want to promote this issue to.” Activist, Africa (P16)*

Thus, sub-division and prioritisation of different elements may hold potential for advocates to deliver clear policy messages, something which palliative care has traditionally struggled to achieve as has been discussed. Additionally, sub-division may lend itself to increased clarity regarding just what a ‘minimum package’ of palliative care, which is of real import as the palliative care community seeks to better engage with global priorities relating to Universal Health Coverage.

With advocates keen to place palliative care within such global-level priorities, it is appropriate to now consider participants' perceptions of the challenges and opportunities for palliative care advancement amongst the current global governance system.

## **Theme Five: Global Policies, Leadership and Actors for Change**

*“Why do we need palliative care, because we don’t have money to pay [for] health, spending the money in the way we’re spending it now, it’s impossible to give better primary care to the populations, we cannot sustain the health system” Physician, Europe (P06)*

As identified throughout this study, global level policies and national-level practices are inextricably linked. Within such relationships, the power dynamics are varied, with different types of policy able to influence national governments in different ways (see Chapter Three). Certain policies are enforceable (international laws), whilst others provide attainable standards which governments are expected to enact (conventions) whilst others serve to limit practices with the aim of preventing harm (regulations).<sup>iv</sup> Within this environment, a wide range of actors operate to both influence change in policy approach as well as to enforce existing policies. Additionally, the complexity of the global governance landscapes means that certain actors and policies may serve to create an enabling environment for palliative care development, whereas others may act to limit such progress.

Different actors hold different levels of relative power to achieve influence.<sup>iv</sup> Further complexity is raised in terms of the development of policies which are truly ‘global’, by which is meant, applicable and relevant to all regions of the world. Such circumstances present acute challenges in the formulation of policies relevant to palliative care, where the distance between global policies and

individualised patient-care is great. As such, discussions included comments upon the transferability and appropriateness of global-level policies to different national contexts.

This theme therefore, reviews the views of participants regarding the existing international policy landscape, to consider its likelihood to lead to further palliative care development. Furthermore, key actors are identified who are seeking to affect such change. Following concerns regarding the sustainability of health systems presented above, the sustainability of palliative care development is critiqued based upon emerging questions relating to the sustainability of pioneer-led models of development and bilateral funding relationships. On this basis, the potential for structural and sustainable change is reviewed within the context of existing and diverse global guidance and policies.

Emerging commonly from such discussions were ideas regarding both the need for more ‘leadership’ both within nations and from global actors as well as examples of where effective leadership both by individuals and organizations has affected positive change towards the further development of palliative care.

### **Leadership**

A range of issues relating to leadership emerged. In terms of global-level leadership, almost all participants looked towards the World Health Organization (WHO) with almost universal approval of their work. A clear example emerged from Africa where one participant suggested:

*“The WHO has provided great leadership on palliative care. They recognise palliative care from the beginning, from diagnosis, so we are using that as, the global community has been using that as underpinning phrase for palliative care globally, and the WHO has also done the Resolution for palliative care, and that has given a huge credibility for the debate around palliative care. So that is increasing the awareness of palliative care at global level.” Activist, Africa (P16)*

As previously addressed, the need for increased awareness of palliative care issues at global level is acute and certainly participants concurred that WHO leadership was both necessary and occurring. In policy terms, this leadership has been crystallised in the passing of the World Health Assembly Resolution ‘Strengthening of palliative care as a component of comprehensive care throughout the

life course'.<sup>lvi</sup> Participants universally ascribed value to the passing of this Resolution. Commenting upon the current policy climate at global level in in this regard:

*I think it's better than it ever has been, for, the global development of palliative care, country, I mean the Resolution passed unanimously and essentially, member states are countries calling on themselves to develop palliative care to include palliative care in their healthcare systems and they've never done that before, and now we have that a tool to use, and I think we actually have a window of opportunity in the next few years to really promote global palliative care development, which may fade over time." Physician, North America (P03)*

Agenda-setting by the WHO and the signing of the Resolution by member states, are encouraging signs, however further discussions raised doubts regarding what the Resolution could feasibly hope to achieve. By their very nature, Resolutions are a formal commitment, yet there are no consequences for failing to live up to these voluntarily incurred obligations.<sup>liv</sup> That is, that there is no enforcement mechanism for governments who fail to enact the terms of the Resolution. One participant acknowledged the importance of the Resolution, as well as its limitations:

*"I think certainly as an international community... for those participants, the delegates for each country to make that vote publicly and in front of the world is a very very strong, a very strong first step... and the very fact that the topic was raised and responded to with that alacrity is very important. The actual then mechanism of process from that point on, of how countries pick up that vote that they've made, how they move with that vote I guess, that's the question isn't it? And you're quite right, there's no absolute enforcement, there's no tribunal which will penalise a country." Physician, Australasia (P14)*

In short, there is a lack of formal accountability mechanisms to hold governments to account, in circumstances where they do not fulfil their obligations. Further discussion regarding both formal and informal mechanisms for accountability will be discussed in due course following additional issues which were raised in terms of global and international leadership.

Instances of positive leadership sat alongside a perceived need for greater leadership within the field of palliative care. One participant was included within the study population to represent a distinct stakeholder group, representing the charitable arm of a private company which sought to address

this perceived lack of leadership through an international training course in Europe. Having identified that often many palliative care 'leaders' were clinicians who were given into managerial and advocacy roles having not had any formal training as to how to perform them as described here:

*"We noticed that there are a lot of very competent people in palliative care, and the people that work in palliative care, you know, they know what they're doing, they know exactly how to treat a patient, and they're very caring towards that and these people often slip into managerial roles. They become heads of hospices, or they become, I don't know, advocacy, or they're heading some kind of organization, and although they are, you know, they know what they're doing on a practical basis, that they sometimes just don't have the managerial skills required to lead a team, or they've never learned how to lead a team. So they're sort of doing it, learning by doing." Program Officer, Europe (P08)*

What this suggests, is that in many circumstances, palliative care professionals are often thrust into situations for which they have no training. In this regard, whilst the emphasis in terms of education within this study has been upon the need for greater international awareness and understanding of palliative care, the field of palliative care itself has much to learn in terms of developing and leading service development within the broader healthcare architecture.

This circumstance raises related issues concerning the sustainability of palliative care development. Pioneer-led models of development are common around the world, whereby motivated professionals, with palliative care skills have driven progress in palliative care in other national contexts. However, such models may be personality-driven and this perceived lack of leadership skills, causes concern for when such personalities discontinue their work. Commenting on what has occurred in Australia one participant reported favourably, but with implicit caution:

*"In the very early days it was those inspired champions that move and shook. Perhaps, not so much the medical establishment, but just the sense of the purpose of our palliative care, and there was quite a missionary zeal almost, for many of them. I think that [there is] a danger of course, where the pioneers, don't attend to that issue of succession...The best leaders in this country have had that ongoing perspective,, I suppose part of it was the very fact of educating a whole group of junior doctors, who then became senior doctors, in palliative care, and a great sense of contentment that those doctors had been trained well and that services could be handed over, to those doctors. So there will be still, probably half a dozen of the*

*pioneers are still living, but retired now, and I think on the whole that succession has been smooth.” Physician, Australasia (P14)*

This is a long, but important quote, which illuminates two things. Firstly, that one way in order to affect structural change may indeed be, to follow WHO guidance and place ‘education’ as the cornerstone for the sustainability of development. Secondly, it contains a warning regarding this issue of ‘succession’ and the potential for deceleration and even a rolling back of progress if and when strong personalities who have developed pioneer-led models move on.

Thus, it appears that a lack of leadership has been identified as a problem and that some solutions are being put into place in order to address this. Yet, it should be noted that the leadership training initiative described above, is not being provided by member-state funded International Organizations, but the international charitable arm of a private company, as philanthropic endeavour. Furthermore, this is a short-term program, taking place only in Europe. Where is such leadership coming from for other world regions?

One participant reported upon an educational initiative emanating from North America, which is seeking to address the same perceived lack of leadership in Africa, Central Asia, Eastern Europe, Latin America, the Middle East, and Southeast Asia. This program arose due to similar perceptions of the existence of able people, being asked to operate in roles outside of their skills and experience as above. Describing how the initiative was conceived:

*“There was a real recognition that there were a group of international people who were palliative medicine consultants, but really needed leadership skills training” Physician, North America (P13)*

The same participant reported that the initiative was indeed having success through the empowerment of new national-level leaders:

*“It’s actually quite staggering what some of these people have done. Way beyond what a typical graduate in the UK, or the United States would do, these people are really advancing palliative care in their country, and they’re often doing it with great difficulty.” Physician, North America (P13)*

Such examples reinforce the need for leadership, as well as how it can be beneficial for palliative care development. Yet, it is important to note, that once more, such initiatives have not been driven by kind of member-funded International Organizations or national governments and again is funded by philanthropy. This is significant, as such funding streams are often short-term and moreover, do not represent commitment from the formal international community to further palliative care interests.

In this sense, leadership is occurring at national, international and global levels, though with different emphases. No global-level funding streams emerged from interviews which fund such leadership programs towards the enactment of the WHA Resolution and this has been left to civil society organizations to plug this gap.

In this regard, different civil society actors emerged as important actors in terms of holding governments accountable for to their responsibilities to globally-set policies. The following section therefore considers the very appropriateness of global policies in terms of their potential to further develop palliative care on a global scale. Moreover it considers how civil society actors are working within the global policy landscape and alongside other actors to advance palliative care interests within national contexts.

### **Civil society, accountability and appropriateness of global policies**

Aside from the WHO, other organizations under the umbrella of the United Nations, emerged as actors with roles to play in the development of palliative care including; United Nations Children's Fund (UNICEF) and the United Nations Human Rights Council (UNHRC). Discussions in this regard, applied to assertions that access to palliative care should be a human right and that failure to ensure access, is tantamount to cruel and degrading treatment, or torture. A more detailed account of how such arguments are constructed and their validity is provided in the final theme, 'Framing Palliative Care'. However, here the focus of discussion is upon how participants viewed civil society organizations play a role in holding governments to account through lobbying, with a focus upon access to pain treatment. Additionally, questions regarding the relevance of rights-based arguments as global policies to all world regions are presented.

At the time of interviews, the Sustainable Development Goals were on the cusp of finalisation. As was identified previously, no palliative care indicator has been included against which governments may be held accountable to their obligation to provide palliative care as signatories of the WHA

Palliative Care Resolution. In this regard, other approaches to holding governments accountable occupied a good deal of discussion.

Several global level actors were identified as having roles to play in the assurance of citizens' rights to pain treatment. Human Rights Watch (HRW), an International Non-Governmental Organization (INGO) emerged as a key actor for holding governments to account for failing to ensure access to palliative care essential medicines. Describing their work:

*[They] have basically done research and advocacy in about a dozen countries looking at what barriers patients who need palliative care encounter, and analysing what the policy reasons for those barriers and then we have been conducting advocacy in order to try and convince governments to, to take steps to remove the barriers we have identified.” Activist, North America (P12)*

Such efforts aim to educate governments as to their obligations, as well as holding them to account, where government actions (or inactions) fail to take necessary steps to meet their commitments to human rights conventions. Describing the situation in India, prior to the easing of regulations which previously served to restrict access to morphine:

*“There was something like 29 regional cancer centres, which are supposed to be comprehensive cancer centres, and the majority of those did not have morphine, even though, 70% of their patients had incurable cancer and the vast majority, of them actually needed morphine. Now, that’s a clear cut situation, I mean, clearly there’s no, the government knows what’s going on, it acknowledges that the regulations are causing an enormous amount of suffering, and yet you have major cancer hospitals, that see tens of thousands of patients per year who are dying of cancer that do not actually have the medication.” Activist, North America (P12)*

Such enforcement requires nuance in order to influence change in governments' policies. It is, for example, of no use for such organizations to approach governments overly aggressively accusing them of human rights abuses, in particular when as has been addressed palliative care issues are often not well understood by policymakers. However, as the above quote shows, a more direct approach *is* appropriate when governments are aware of their obligations but fail to take the necessary measures in order to meet them.

However, HRW does not act alone and there was acknowledgement by participants that a confrontational approach needs to be accompanied by more enabling assistance. In this regard, organizations such as the International Association of Hospice and Palliative Care (IAHPC) and the Worldwide Hospice Palliative Care Alliance (WHPCA) and other international-level palliative care organizations have adopted a two-pronged approach to holding governments accountable to human rights obligations. One participant described this dynamic:

*“Governments are actually a bit peeved when you come at them with human rights, it’s a confrontational discussion, but that’s one of the reasons why Human Rights Watch and WHPCA and IAHPC, have such a good partnership, because Human Rights confronts, and we say ‘how can we help you improve’.” Physician, Africa (P07)*

Success stories regarding the use of such an approach were also identified. In Mexico, for instance, it was described how prohibitive government regulations limited physicians’ ability and willingness to prescribe morphine. Through awareness raising and education by HRW, the government recognised that it was their own regulations which were causing people to suffer extreme pain, without appropriate medications and changed the regulations to facilitate easier prescribing processes and increase access to pain relief. Similarly, in India, prohibitive regulations were tackled through actors at global level, lobbying the national government, in tandem with actions by national-level palliative care activists:

*“I feel that what has happened is that India has signed the Convention on Narcotics, which it had not done any work on and organizations like Human Rights Watch, the WHO, had been very critical about it and I must pay tribute to people in the palliative care arena, who have been campaigning for you know, better opioid availability, for making palliative care a part of the National Health Program” Physician, Asia (P04)*

This quote highlights the interaction between global level action and national policymakers, most notably in this instance, Ministries of Health who were identified as key actors for change. Yet, alongside successful examples of rights-based approaches to lobbying governments, evidence also emerged to suggest that rights-based arguments are not necessarily well-received, or relevant, in all world regions as referred to below:

*“I can understand, the perception of an individual right to have access to care as a political statement, as if to get governments to provide for their citizens, but, in some of the Eastern cultures, right is, you can have rights, but the right doesn’t always reside with the person... and it is seen in Malaysia for example... as a very secular way of dealing with things, whereas if you look at countries where they are more inclined to be spiritual and religious, the right of a man, the right of a human are very different from a human rights approach... I agree with the concept of human rights in palliative care, but I disagree on how it can be used to effect change, and I prefer to use things like ‘responsibility’ and ‘duty’, I think you can achieve the same thing by using a different approach.” Physician, Asia (P05)*

It is well known that approaches to palliative care development must include adaptation for local context.<sup>lvii</sup> In this regard, the above quote is significant, as it suggests that regional approaches to advocacy may also be appropriate. Regional palliative care associations were identified in all regions of the world, however, in terms of advocacy doubts were cast upon the possibility of a regional approach:

*“Can something be done at say regional level, I think that it’s actually difficult, because of the global environment now, you know, information is shared across the world, there is sometimes a challenge to follow what is done in different countries. Many indices and measurements are done globally as well as regionally, the quality of death index in 2010, done by the Asian Intelligence Unit, looked at 40 countries, and so, can you look at that regionally? You look at it globally.” Physician, Asia (P05)*

The quote is suggestive of ongoing processes of policy diffusion, whereby, what occurs in one country or region can have influence beyond borders. Additionally, it highlights the challenges of formulating global-level policies which are universally relevant in all regions. This question of which palliative care issues are ‘universal’, occupied much discussion with participants. For instance, universal truths were identified regarding mortality as well as physiology. However, even such universal experiences are not necessarily conducive to prescriptive, one-size-fits all policy approached as suggested here from the context of educating physicians in low-resource settings:

*If I’m doing pain management for example, the pharmacology is the same, the approach to assessment is the same, teaching that, what’s different is, ‘what drugs do they have?’ Physician, North America (P13)*

In this regard, whilst the INCB regulations allow the use of strong medications in all national settings, medical practice remains dependent on the resources which are available within any one country. Therefore, global policies have to be general enough to cover all settings and often navigate this complexity by focussing upon 'essential medicines'. This has led to an absence therefore of specific targets relating ensuring access to cheaper drugs such as oral morphine, and allows nation states to be compliant with regulations, even if they only ensure the availability of expensive drugs. Therefore, whilst global-level regulations do not specifically prohibit access to opioid analgesics, it does not necessarily follow that, this makes existing regulations 'appropriate'.

The importance of discourse was once more identified as relevant here. Essential medicines are regulated at global level by the International *Narcotics* Control Board. That is, the same organization which seeks to inhibit access to illicit drugs. Commenting upon this in terms of access to essential treatments, one participant commented:

*"That's part of the deal, to stop calling them drugs and start calling them medicines" Activist, North America (P02)*

Furthermore, signatories to the United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances, 1988, operate within guidance which tonally suggests that 'drugs' should be *restricted* rather than enabled for medical use. Additionally, this convention is distinct, as unlike other Conventions and Resolutions addressed in this section, as it has a formal accountability mechanism in terms of the INCB. However, more commonly organizations such as the World Health Assembly, lack both the power and the resources in order to implement their own policies.

With this in mind, it is appropriate to consider which global level organizations *do* have the resources in order to effect change through direct processes of policy transfer. On this basis, the analysis proceeds to discuss participant views on global financiers which are relevant to palliative care interests.

### **Global level funding streams**

Arguments were presented relating to how a reallocation of existing healthcare resources, both in terms of financing and human resources, offered a realistic and sustainable model for palliative care

development in Theme Four. However, alongside such discussions was awareness that new sources of national and global level financing were needed in order to achieve progress. Before considering potential new sources of funding, firstly, existing funding models which exist internationally will be reviewed, in terms of both their adequacy and their sustainability.

As identified above, philanthropic organizations, most notably the Open Society Foundation (OSF), were identified as being funders of both palliative care services as well as educational initiatives. As the following quote illustrates, however, concerns were revealed regarding an overdependence upon this funding stream:

*“Well, up until now and it’s drying up, it’s been from the Open Society Foundation, I mean, Soros<sup>1</sup> has pretty much funded this stuff single-handedly. USAID has done a lot, but in terms of palliative care funding, there’s almost none, except through private philanthropy, and in fact, civil-society is doing member states jobs and doing the work of the International Financial Institutions, like the World Bank.” Activist, North America (P02)*

Many participants pointed to the important role which the OSF has played in funding development, yet it is an overstatement to say that they have done so ‘single-handedly’. However, real questions are raised regarding both the sustainability of and reliance upon on this source of funding. Although such organizations will operate with varying degrees of autonomy in terms of where they direct funding, in some sense, the involvement of philanthropists is consistent with ‘pioneer-led’ narratives of palliative care development. That is that individuals, in this sense both in terms of persons as well as organizations are driving development. Such involvement from civil society organizations is to be welcomed. However, this model raises grave questions regarding the sustainability of funding streams, whereby, priorities and interests can change, hinted at by the reference above to funding ‘drying up’. Furthermore, short-term grants do not allow long term strategic planning without the involvement of additional stakeholders.

As well as philanthropic organizations, similar critiques may be given to funding streams given by charitable organizations. In the context of Africa, the Diana Princess of Wales Memorial Fund was identified as being a key funder of Hospice Africa in Uganda. Yet, in spite of the professed success of the ‘Uganda Model’, it was revealed that in spite of their classification of a country which has

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<sup>1</sup> George Soros is a billionaire philanthropist who has funded many palliative care programs through the Open Society Foundation.

achieved ‘full integration of palliative care into the health system’, it remains reliant on such charitable funding streams. As one participant reported:

*“Even now, they do work with money from donors, with very limited support from the government, despite the integration, so that is an area where it is lacking in terms of integration.” Activist, Africa (P16)*

This ongoing need for funding is not a problem isolated to one world region. In the United States (US), another country which has supposedly successfully integrated palliative care into the health system, hospices continue to have to raise their own funds through charitable work. This point was noted, alongside risks regarding equity of access, where services are reliant on benevolence:

*“You can’t really have an impact if you’re going to be outside the system and you’re going to just use charitable dollars to take care of a few patients, which somebody called, ‘deluxe dying for the few’” Physician, North America (P03)*

The funding provided by philanthropic and charitable organizations as presented, once more demonstrates the key role which civil-society organizations have played in the international promotion of palliative care. What then of the key multilateral global health financiers?

As noted above, USAID was identified as having had involvement in the promotion of palliative care interests following involvement of the now defunct President's Emergency Plan for AIDS Relief. Whilst the involvement of such agencies with their high levels of potential resources should be considered positively, their involvement was, identified in the context of palliative care need relating to HIV/AIDS only. Referring to experience working with USAID it was suggested:

*“They supported the palliative care but it was from the perspective of HIV/AIDS” Pharmacist, Europe (P01)*

Whilst all support for the furthering of palliative care may be welcomed, a disease-specific approach to development is not in line with a key message which advocates are trying to deliver, that palliative care is needed for *all* serious and incurable illnesses. Furthermore, consistent with an approach which supports nationally-devised priorities, the support of USAID was perceived as reliant upon governments *requesting* funding for palliative care:

*“USAID, in Kenya, they come to speak to the Ministry of Health in Kenya and say, ‘what are your plans?’, and the Minister of Health says, ‘these are the things we are tracking’. If palliative care is not part of the thing that the Minister of Health is tracking, it’s never going to be included in the USAID Country Operating Plan.” Activist, Africa (P16)*

This hints at the potential for greater involvement of USAID, however, concerns must also be raised, due to the broad lack of awareness of palliative care amongst national policymakers as has been described. Furthermore, there is ongoing need for funding for palliative care not only at national level, but at global level itself. The WHO has been identified as facilitating the development of palliative care through the issuance of guidance. However, even global organizations are being hamstrung by a lack of financing to further palliative care interests as reported here:

*“Unfortunately, the WHO doesn’t have much money because since 1992 the states’ contributions have hardly increased, they followed inflation, but, that’s all. There was a palliative care resolution you may be aware of from the World Health Assembly last year that’s also requesting WHO to develop more pain guidelines. But, the funding is the problem there.” Pharmacist, Europe (P01)*

Thus, scarcity of funding is an issue which exists at all levels of global health governance. In this regard, it was suggested that civil-society is performing roles which should be the responsibility of national governments and global funding agencies. Indeed, although many actors within civil society have been real drivers for change in terms of palliative care development, emerging frustration was identified at the lack of engagement of many actors who were deemed to be not living up to their obligations with regards to palliative care, with one activist asserting:

*“Civil society, academia, many of the colleagues that we all know are doing governments’ work for them and they’re doing the IFIs [International Financial Institutions] work for them and they’re doing, you know, the regional associations work for them and it’s time for governments and the UN and the World Bank to step up to the plate and stop letting us carry the water for them.” Activist, North America (P02)*

Owing to the key roles played by civil society individuals and organisations in driving palliative care development, frustration in this regard appears justified.

Organizations such as the World Bank have both the financial resources, as well as the technical expertise, necessary to both influence and support national governments in developing sustainable palliative care systems however they are simply not doing so. Indeed, a key area of consensus amongst participants was the assertion that a wide range of stakeholders held responsibilities which they were not fulfilling with regards to palliative care.

Finally, as well as their roles as service providers, mechanisms for accountability and funders, one final role which civil-society members could play acting as drivers for change was identified, as advocacy. There was consensus amongst participants, that the way to engage new stakeholders at national, international and global levels was through targeted advocacy campaigns. It follows due to the diversity of potential stakeholders which it was suggested should be targeted through advocacy, that a multi-faceted approach would be necessary, which utilised all of the varied ways in which arguments may be made for further development of palliative care.

## **Theme Six: Approaches to Advocacy and Framing Palliative Care**

*“What is our contribution to the wider debate? What is the contribution of palliative care to saving mothers, what is the contribution of palliative care to saving HIV? You know?” Activist, Africa (P16)*

As described throughout this study, policy issues may be presented in different ways, using different ‘frames’ to describe the same problem/solution (See Chapter Three). Different frames hold differing potential to influence different actors. Similarly, ‘frames’ are said to have relative power to achieve change, with ‘national security’ issues said to hold the highest likelihood of influencing national policymakers.<sup>vi</sup> Within this theme, participants’ views of the varied ways on which arguments can be made for greater roll out of palliative care services are given. Prior to presenting each of these ‘frames’, a brief discussion of participants’ perceptions of more general issues relating to advocacy is given in terms of; ethics, strategic partnerships as well as potential targets for advocacy at both national and international levels.

### **Key issues for advocacy**

Thus far, a wide range of opportunities and barriers have been identified to the further development of palliative care. In this regard, there are many of issues advocates must engage with, in order to overcome obstacles and capitalise upon areas of potential gain. Within a context of different advocacy lobbies competing for attention, one participant and experienced advocate described their work as:

*Mainly looking at how palliative care can be integrated into drug policy, donor financing, international NGOs, international policies and making sure that other people really get aware, academics and research, making sure people get aware, get more knowledge and information about palliative care. Activist, Africa (P16)*

These are diverse foci, comprising many issues and actors. They address issues relating to access to medicines, finance, partnerships, policies and raising awareness through education as well as a need for an improved evidence-base. Issues relating to 'access' within this study have primarily focussed upon access to pain treatment and palliative care, however such issues also appear in terms of advocacy. A further challenge to advocates relates to gaining access to those whom they seek to influence. One participant described this barrier to advocacy along with some suggested organizations who palliative care advocates should be seeking to influence, from a perspective of paediatric palliative care:

*"The big UN agencies, of course, WHO, USAID, UNICEF, all of these we are acting with, at present, we actually have a side-event at the World Health Assembly in two weeks time specifically for paediatric palliative care, so that's where we're really going to give the message around paediatric palliative care, but I think you know, also... global level funders, like Global Fund, USAID, the Gates Foundation, it's just finding a way to get in there. I'm sure if we could get in there we could make the argument, but it's not that easy..." Nurse, Africa (P06)*

The quote describes to some extent, how merely 'holding a seat at the table' and being present at policy events increases the likelihood of advocacy messages to be heard and understood by policy actors. Additionally, the key challenge of gaining access to policymakers who hold no pre-existing interest in palliative care is suggested, raising the question of how can you influence people whom will not hear your voice? This is a challenge faced by all advocacy lobbies, however one way in which

to increase the reach of an advocacy message is to form partnerships. Describing their work with the International Association for Hospice and Palliative Care (IAHPC), one participant reported:

*“We are an NGO in formal relations with the World Health Organization and in this capacity work with governments, policy makers and the civil society of many different countries. We maintain relations with presidents and directors of national and regional palliative care associations and programs throughout the world.” Physician, South America (P09)*

Once more the importance of ‘a seat at the table’ is referred to whereby advocates are involved with global level health discussions on an ongoing basis. Partnerships were referred to in the previous theme, where a two-pronged approach was adopted by HRW and IAHPC to both confront national governments who were limiting access to pain medications as well as to assist them, more supportively through technical assistance on how to address the issue. Additionally, partnerships were one way in which it was suggested that palliative care advocates could engage with pharmaceutical companies on issues of shared importance. As referred to previously, much palliative care advocacy has prioritised the issue of access to essential medicines, an issue where the importance of policies which enable access to medicines, rather than ones which aim to restrict their use are paramount.

Although participants identified existing and potential partnerships which may be able to further palliative care interests, it was notable that almost all examples related to actors involved in the field of palliative care. This suggests that advocacy efforts have thus far not focussed upon new potential allies outside the field or that they have been unsuccessful in forging any such partnerships. Instead, common narratives related to how cognitive change of actors not currently involved with palliative care could be achieved through experiential learning, or the elicitation of improved attitudes towards palliative care through story-telling.

### **Experiential learning and story-telling**

Many participants attributed a high degree of value to the idea of changing perceptions and gaining influence through ‘story-telling’. What is meant by this is that through the presentation of palliative care narratives, which describe the patient journey, from illness related suffering, to improved quality of life once palliative care is introduced, new actors could be engaged with palliative care issues. Such an approach was said to be more effective, when it resonated with the personal

experiences of advocacy targets:

*“I’m aware... how an audience can be transfixed by a story...the striking nature in palliative care and I think there’s an innate, intrinsic intensity when you start to talk about an ill person who may be close to dying... and telling stories I think can be quite profound for policymakers, and indeed it may be their own personal stories, the loss of someone in their own lives that might be a catalyst, and quite a significant catalyst, for them to start to think along the lines of better access to opioids, or about palliative care” Physician, Australasia (P14)*

This relates to ideas of experiential learning and plays upon ideas of moral obligation. Such issues will be returned to in subsequent sections, however, in terms of strategy, the idea of story-telling, either orally or visually, was recurrent within participant discussions. One participant reported how ‘patient narratives’ have been used to raise awareness of the consequences of *absence* of palliative care, as well as the benefits for patients once it is accessed. Describing the complicated ethical issues which arise in terms of the use of images and stories of suffering:

*“If you look at the palliative care it has evolved showing lots of graphic images and people in pain and screaming and that is absolutely not good, it’s counter-productive, and we don’t want to show, to even increase vulnerability for people who are already vulnerable. So, the way we have done this is to capture the voices of people, people giving their story...We have patients come to give testimonies, but these are not patients who are bed-ridden and having all these graphic photographs of patients, it’s a person saying ‘when I was in pain, this is what happened to me’.” Activist, Africa (P16)*

Issues relating to how the moral argument for palliative care is constructed will be returned to. However, this suggestion of influencing policymakers through experiential learning is one which was said to gain attention as described by one physician:

*“I think the experiential effect of knowing somebody who has received palliative care, reverberates around the community, and that, changes perceptions, it raises expectation. I was looking after a Minister’s mother, one of the Ministers in the government, and we provided palliative care to his mother and he said, ‘now, if you can do this, why can’t our hospitals do this? Because they had been in their own hospitals and private hospitals, ‘you’re*

*providing a free service and you're doing what others can't do'. I said, 'that's a challenge to you, you're in a position of power...you make the change'" Physician, Asia (P05)*

Once more this approach remains reliant upon individuals and personalities, however, some such individuals may hold the potential to act as 'gatekeepers' for policy change and indeed, individuals such as Ministers for Health hold the power to influence not only national policy, but to garner global level support for action. A previously used example described how the formulation of a national-policy for palliative care allowed engagement with organizations such as USAID, who do not transfer policies 'from above' and instead support issues defined by national governments. Additionally, Ministers of Health hold the power to formulate such national plans to promote national-level action for palliative care:

*"What we say is that for them to make sure there is a national policy for palliative care. The reason why we want them to have a national policy for palliative care is... they are likely to have some funding allocated. Because that is how governments allocate their grants, whatever they are funding, whatever is in policy that is what they support." Activist, Africa (P16)*

A further strategy for advocacy which was identified related to engaging actors such as communities and the media in order to raise awareness of issues relating to palliative care. In terms of community-engagement one participant described a local initiative:

*"Here in Kenya, the Kenya Hospice and Palliative Care Association, has been very very, active in doing public profiles, they do walks, they do like a public walk, where they talk about why they are walking the streets, they have t-shirts, talking about suffering, you know, 'let's end suffering', they have all these t-shirts, and they don't say what suffering it is, and people ask, 'what is this suffering you are talking about?'" Activist, Africa (P16)*

Such an approach focusses upon fostering community engagement by increasing understanding and starting conversations regarding the importance and need for palliative care. Additionally the importance of a message such as, 'let's end suffering', which is at once clear but at the same time vague enough to provoke debate appears likely to encourage both discussion and understanding. All such strategies must, however, be multi-faceted as the impact of such 'public walks' is likely to be

felt at community level only. Considering the national level, the importance of engaging the media was described in such terms:

*“There are so many different ways you can start public debate. Go to the TV, go to the Radio, and start a conversation, everybody in Kenya, 90% of people in Kenya have a radio, have a conversation on the radio, have people call in and ask questions, really use some of the generic ways we give people information, do a newspaper spread.” Activist, Africa (P16)*

This is a useful example, which demonstrates the value of locally-relevant advocacy approaches. Here the communication media suggested is ‘radio’ due to the wide audience which can be reached, however, in other contexts a different approach was adopted, which once more played upon locally-relevant issues. Ruing what they perceived as the failure of the palliative care community to present itself effectively, as well the need to provide a message which is publicly acceptable, one participant commented:

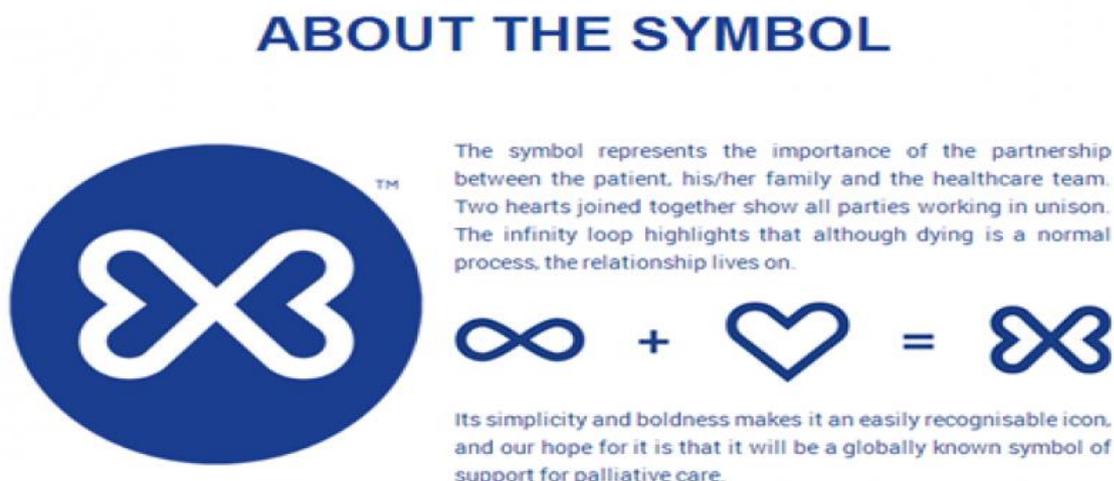
*“When you look globally, there’s a lot of discussions around end of life care, and things like, I think there might be a session here on ‘the good death’, anything to do with death is not good, and whilst palliative care people are very open to talk about death and dying, the general population are not. And I think that’s where we do need better people at things like ‘selling the product’, marketing. Physician, Asia (P05)*

This discussion continued following the conclusion of the formal interview and the participant described how their organization has produced awareness raising short videos, presented by national celebrities, which are played in national cinemas. Once more, such efforts are aimed at increasing awareness and fostering discussion, with the involvement of celebrities to deliver the message, an approach consistent with one element of a ‘successful advocacy strategy’ as suggested by WHO.<sup>lxix</sup> Similarly, the same participant described an additional local initiative:

*“We’ve created a symbol in Malaysia to hopefully try and change perception” Physician, Asia (P05)*

Real value was attached to the idea of symbolic representation of what palliative care is, the justification for which is presented in Figure 39.

Figure 39: Symbolising palliative care



Source: Hospis Malaysia, 2014<sup>lviii</sup>

The use of symbols has been prominent in other successful advocacy campaigns, for instance the ‘red ribbon’ which is used to represent the fight against HIV/AIDS and is commonly understood. Once more, the use of symbols is in line with WHO guidance on how to conduct an advocacy campaign.

However, symbols can only have meaning if they represent some kind of shared understanding. This is problematic in terms of ‘palliative care’ owing to the diverse ways in which the term is understood. In order to better understand the ‘key message(s)’ which advocates seek to present to policymakers, direct questions were asked regarding the diverse ways in which arguments can be constructed for palliative care to different audiences. Informed by Labonte and Gagnon’s study<sup>vi</sup>, which ranked different ‘frames’ in terms of their relative likelihood of achieving policy change, here, the diverse frames with which advocates are seeking to present to policymakers are presented in order of their relative potential of achieving influence.

However, as no characterisations were given within the theoretically ‘most powerful’ frame, health as a national security issue, attention is first given to the second most potentially influential frame, ‘International Development’, or put another way, economic arguments for palliative care.

### **Palliative care as an international development issue**

In order to understand how palliative care may be conceptualised as an international development issue, it is necessary to reiterate one of the key economic aims of development; poverty reduction.<sup>lix</sup>

Furthermore, it is important to understand that this aim may be achieved in one of two ways which are of relevance here. Either, poverty may be reduced by preventing people who are hovering above the poverty line from falling in to poverty, a strategy termed 'poverty avoidance'. A second way is to promote economic growth through the empowerment of people to be economically productive, that is, a 'human capital' approach to development which aims to lift people *out* of poverty. Of relevance here, this means to consider health "no longer simply a consequence of growth, but one of its engines [2010].<sup>vi</sup> This is especially significant, as 'poverty reduction' is unceasingly professed to be a global priority and this commitment has once more been formalised in the SDGs.<sup>iii</sup> Furthermore, international financial institutions such as the World Bank, speak in language in terms of both poverty reduction and human capital, meaning that it may be said, that arguments presented within this frame may hold the potential to engage with new sources of global financing for palliative care.

Several participants suggested ways in which palliative care can contribute to 'poverty avoidance'. That is, appropriately timed palliative care can reduce out-of-pocket expenditure for families, by the avoidance of futile and expensive treatments, which threaten to push people beneath the poverty line as described here:

*"In India I've seen it, where patients are referred to hospitals and for intensive treatment and families go into debt, and they become 'debt-slaves' that's what some of my colleagues call it"*  
Activist, North America (P02)

This was an argument presented not only in low-income settings, but in in the United States also, where many families pay 'out of pocket' for healthcare within a private health system. Commenting in this regard one participant described the consequences of ongoing aggressive treatment in circumstances where palliative care was not accessed:

*"[A] study which was done in the mid-1990s, had two unexpected outcomes... one of which was [that] about 30% of families, even if they are well insured go bankrupt, and in about 25% of families, somebody needs to stop their career to become a caregiver, and loses their future career."* Physician, North America (P13)

This quote adds weight to the suggestion that palliative care may have a role to play in *poverty* avoidance through reduced out-of-pocket expenditure on healthcare. However, participants did not acknowledge that families and carers can actually incur high costs whilst caring for people with

serious illness.<sup>iii</sup> Yet the quote also hints at a second way in which palliative care may be able to contribute to poverty reduction, which we may term the ‘human capital argument for palliative care’.

The ‘human capital’ argument suggests that nations’ potential for economic growth is reduced by patients and lay carers having to cease economic activity due to either illness or caregiving duties. Palliative care is said to be able to reduce such effects in two ways. Firstly, that people who have left the workforce due to their symptom burden may be able to return to economic productivity if such symptoms are effectively managed. Secondly, that when lay carers assume their caring role, that they may have to leave the workforce which may be prevented if they are supported and their care recipients’ condition better managed, that they too may be able to resume economic productivity. This scenario may not be a universal one in palliative care situations, however, as one participant described:

*“Some of the [patients’] symptoms once they are controlled... once pain is managed, some of these people are able to go back to productive work, so it’s helping them make sure that these people stay as healthy, as pain free and as symptom free as possible, so that they can continue with their every day job.” Activist, Africa (P16)*

However, as was discussed within Theme Three on Broad Benefits, this argument is highly dependent upon palliative care being introduced at an early stage. For instance, there is certainly a time in the course of illness where a return to work will not be possible. However, timing may be less important in terms of the benefits for families. Indeed such benefits may persist even when patients and carers are older people who are no longer in employment as such groups play important social roles within communities as described by the PPI representative:

*“[Families/carers] would be making contributions to their local community... If they’re able to continue picking the grandchildren up from school, which helps mother and father work, both work, so they can pay their mortgage, you know, that’s contributing to society and is a positive outcome” PPR Representative, Europe (P11)*

Thus, the benefits may be translated to extended families and support systems.

Both the poverty avoidance and human capital arguments are extremely significant as they are speaking directly in terms of broader global development priorities. Unfortunately it appears that few palliative care researchers to date are providing the requisite evidence to back up such claims a

point noted in Chapter Five. Several studies have shown the links between serious illness at the end of life and increased household poverty, yet, no studies known to the author, show how palliative care can prevent this. That is that although the argument that reduced household expenditure on futile treatments would reduce household poverty appears rational, advocates do not have hard evidence of this to present to policymakers.

A second way in which advocates may be able to integrate palliative care into broader global health development economic priorities centres around the reorganization of healthcare systems to become more efficient, with the aim of achieving Universal Health Coverage. Arguments relating to ‘cost-avoidance’ whereby healthcare systems reduce expenditure on inappropriate care in favour of palliative care have been fully described within the Broad Benefits theme and no do require repetition here. Similarly, the argument that a redistribution of healthcare human resources away from aggressive treatment delivery at the end of life increases health system has been reported in full.

It serves, therefore, to make the point that such a reorganization of health services may reduce costs within health systems, as well as facilitating the benefits relating to the ‘poverty avoidance’ argument. What is less resolved is the financial impact of palliative care delivery which commences at the point of diagnosis and introduced alongside curative efforts. The arguments for cost reduction and cost avoidance appear are convincing, however, without adequate evidence, they are open to be both ignored and disproven and great care should be exercised before exercising rhetorical arguments without sufficient evidence.

However due to relative power of the ‘international development ‘frame’ as well as the potential for palliative care to frame itself, this warrants attention from both advocates and researchers. Indeed the very language of ‘poverty avoidance’ and ‘human capital’ is liable to resonate some of the major global health financiers such as the World Bank who include these as part of both their key aims as well as their strategy. Furthermore, organizations like the Bank have traditionally, discouraged talk of human rights in favour of discourses on human capital.<sup>lx</sup>

However, human rights arguments do hold the potential to influence both national and international policymakers and have been used to affect progress towards the realisation of many social justice causes.<sup>lxi</sup> In this regard, attention here turns to how the human rights ‘frame’ may be used by

advocates, as well as competing rights based claims which may either further, or restrict palliative care development in terms of human rights.

### **Palliative care and human rights**

Rights-based discussions were pervasive with all study participants, both in terms of language used as well as specific articulations of why palliative care is a human rights issue. Human rights issues are, however complex and may exist at the individual level, ie the right to freedom of movement, or at societal level in terms of obligations upon governments to ensure citizens' rights, ie the right to health. Currently, there is no explicit global legislation which states the human right to palliative care or pain treatment. On this basis, the arguments that access to such services *should* be a human right, is based upon interpretation of existing human rights law.<sup>lxii</sup> Although there is some overlap between a potential human right to palliative care and one to pain treatment, here they are dealt with separately, firstly to examine the claim that there is a 'right to palliative care' as part of the existing 'right to health'. A human rights expert within the sample suggested:

*"You have to construct that right. You know, the right to the highest attainable level of physical and mental health. And clearly, palliative care falls within that right." Activist, North America (P12)*

Based upon the premise that palliative care improves both the physical and mental health of patients and carers, this argument is fairly clear. If illness negatively affects quality of life and palliative care reduces such negative effects, it is rational to suggest that 'the highest attainable level of physical and mental health' is not achieved without palliative care. Access to pain relief is implicitly included within this 'right', however, a separate articulation of why access to pain medication is a human right was also reported.

This suggestion is also made within the context of a pre-existing human right that of the right to freedom from torture. The suggestion being, that the allowance of extreme suffering which is caused due to physical pain, when treatments are known to prevent such distress, is tantamount to torture:

*"When you speak to people who are suffering severe pain due to cancer or other illnesses, and who do not have access to appropriate treatment, they really describe their suffering in*

*a way which is very similar to the way a victim of torture would describe their experience. They basically, both groups would tell you that the pain was 'unbearable', that 'they would do anything to make it stop'...So what makes this a human rights issue, is that, that suffering could be prevented, or alleviated, generally, pretty easily with inexpensive interventions, and inexpensive medications and so there's really no excuse for a healthcare system to not provide the service." Activist, North America (P12)*

These arguments that access to pain relief and palliative care share two key tenets. The first is that the rights-based obligation falls upon national governments to provide the necessary services to ensure the rights of their citizens. Secondly, both arguments are based upon the interpretation and co-optation of existing human rights legislation. That is, that it is unlikely that the drafters of the formal rights to health and freedom from torture, had access to pain and palliative services in mind when drafting the legislation.

Further complexity is raised in terms of both rights-based arguments in that in order to elevate the claims into human rights issues, they rely upon a pre-existing knowledge of the benefits of pain and palliative care services amongst national policymakers. That is, that in order to be in violation of such rights, there has to be a wilful intent to withhold pain and palliative care services, the arguments do not hold if policymakers are not aware of how either palliative care ensures the right to health, or absence of pain services results in suffering tantamount to torture.

As a consequence of this distinction between wilful and unknowing failure to provide palliative services, the circumstances in which rights-based arguments may be used are in some ways limited to a role in raising awareness rather than as an accountability mechanism for holding governments responsible to their obligations. Reported in terms of the 'appropriateness' of global policies, it is not useful strategy for advocates to confront national governments of countries which have not palliative care at all by calling them human rights abusers. Similarly, at the individual level, it is not helpful to describe physicians' failure to treat pain in circumstances where strong pain medicines are not available, as 'torturers'. Indeed there was a clear emphasis amongst participants, that human rights in this regard, are governmental responsibilities and that the rights exist at societal level. The only exception to this circumstance was described thusly:

*"Say a physician has access to all the medications and the knowledge et cetera, to relieve someone's pain, but the physician says, you know what, 'you belong to this ethnic minority, I*

*don't like you, I'm not going to give it to you'... Then there is an intent to cause severe suffering and that would be torture. But of course, you know, that's a situation which you don't generally see [laughs]. Activist, North America (P12)*

However, the relevance of conceptualising access to pain and palliative care services was reported as existing at the individual level only in this sense. That is that individuals hold the power to *abuse* the human rights of others, but not to advocate on their own behalf for their realisation. Human rights arguments may therefore be understood as being important as an advocacy tool in terms of engaging national and international policymakers, but not for the empowerment of individuals. Commenting in this regard, one participant reports:

*"I think [human rights is] a healthy argument at global level and at policymaker level, it's not a helpful argument to the recipients of palliative care, I always say, 'its pointless to say to someone who has no food for tomorrow that it is their right to have pain control, it is their right to have food yet they don't have it', so I see it's an important point at the global level... at the patient level, perhaps not as much." Activist, Africa (P16)*

At global level, advocates have had some encouragement for the arguments that there is a rights-based claim for access to pain and palliative services. One participant reported how the UN has been receptive to this conceptualisation:

*"We had a statement from the UN special interlocutor on torture, cruel and inhumane and degrading punishment, that initially said, 'if a government deliberately, willing prevents access to pain relief for its citizens, by essentially banning strong analgesics, that that's an indirect form of torture'" Physician, North America (P03)*

Whilst such support from within the UN may be considered positively, holding governments accountable to their rights-based obligations is an ongoing concern for the UN, which lacks a great deal in terms of power of enforcement. Nevertheless, one participant did report that human rights legislation does present opportunities to hold governments accountable to their commitments:

*"There's no absolute enforcement, there's no tribunal which will penalise a country, but I guess I probably would link that vote with the Committee which oversees the International Covenant on Economic Social and Cultural Rights, which has the main articulation of the right*

*to health, so for instance, that Committee could well say to country a b and c which appear before it, 'let's talk about your fulfilment of the international right to health, and we do note, that you as a country a did vote, did make that vote at the International Health Assembly, so it's, so you're conscious of this, what therefore are you doing about it?'" Physician, Australasia (P14)*

Yet, the UN has not been fully successful in guaranteeing existing rights – let alone prospective additional claims. In this sense, questions are raised regarding who exactly are the targets for rights-based arguments? Normative agencies like the UN appear to already be notionally on side. Additionally, national governments of countries where there are no palliative care services are perceived to be poor targets for rights-based claims, which appears to leave only national governments who are presiding over prohibitive opioid regulations as the key targets for rights-based advocacy. Again, this raises questions regarding the appropriateness of human-rights approaches in all world settings.

However, there as has been a recent success emanating from rights-based 'frame'. At the time of interview, one participant reported:

*"In the Americas, countries are negotiating a new treaty on the rights of older people, and that treaty, well, the text of that draft treaty right now includes an explicit right to palliative care." Activist, North America (P12)*

These negotiations were conducted within the Organization of American States and indeed agreement was reached to recognise a formal right to palliative care for older people.<sup>lxiii</sup> It remains unknown how this right will be realised, however, it's inclusion as a formal right represents a step forwards for rights-based activists and may be a significant tool for advocates to use in terms of holding governments accountable to their obligations in the region. Indeed formal recognition of a right to palliative care within a regional, but international organization may prove to hold influence even outside the Americas, in terms of actively spreading international norms and values. Less formal rights-based language was also endemic during interviews. Additional to formal rights-based 'frames', participants often spoke in more general language referring to 'rights'. For instance, the PPI Representative asserted that:

*“I think that everybody has got a right to a pain free and dignified life and death.” PPI Representative, Europe (P11)*

Other participants spoke in terms of a ‘right to autonomy [Physician, North America (P12)]’ and a ‘right to self-determination’ [PPI Representative, Europe (P11)]. Though such comments were not further articulated into serious rights-based claims, they raise further questions regarding the legitimacy of a ‘human rights approach’ which *may* be considered as a mechanism for the transferral of ideologies. That is, that whilst some participants spoke in terms of this ‘right to autonomy’, in the Asian context, this was not understood in the way in which it was intended. The distinction is reported here by a participant from Asia:

*In many Asian communities, [autonomy] is seen as collective rather than individual, the family structure becomes more important than the individual, and so, I like that in recent years, the discussion on autonomy, because autonomy is always seen as the rights of an individual, I like that some of the discussions have now been about relational autonomy, the right of one, has to be in relation to another.” Physician, Asia (P05)*

In this regard, the power of the human rights ‘frame’ is shown to be further limited due to further restrictions upon the contexts in which they hold relevance.

A further complexity of framing palliative care as a human rights issue arose in terms of how such arguments relate to other rights-based claims. Conversations in this regard referred almost exclusively to the ‘right to die’ movement. Many participants characterised a potential right to die as something to be avoided. Often participants made clear that they were representing their individual views, though there were some references to organizational resistance to right-to-die claims:

*“What we say as the International Children’s Palliative Care Network, and very clearly we have a statement about this, is that ‘assisted dying is not part of palliative care, is that it’s not an extension of palliative care, palliative care is about quality of life, a good death, but a good death which comes in its own natural time and supported’, so, we’re very clear about that.” Nurse, Africa (P06)*

Moral and ethical perspectives appear to be the main argument for resistance to the right-to-die movement, centring around assertions that the reason that people may request an assisted death is

due to intolerable suffering. Suffering which, it was suggested that effective palliative care has the potential to relieve. Speaking in this regard one participant reported:

*“Palliative care allows you to die with dignity, pain free, with comfort, with not necessarily an acceptance, I mean, I’ve nursed many patients and I know a lot of people fight to the end, but it preserves the dignity and it accepts dying as normal, if you were using it against an argument against assisted dying, and we often talk about palliative care being the answer to assisted dying, because if we can provide that comfort, that support, that relief of symptoms, spiritual care and all of that, you need good quality palliative care, then we would think that a lot of people who would like to end their lives, would change their mind.” Nurse, Africa (P06)*

Some softer attitudes were however revealed regarding a potential right-to-die. In this sense, the argument was that conversations on issues relating to assisted dying and euthanasia were premature whilst palliative care remains so underdeveloped around the world. Though not explicitly rejecting a right-to-die, participants suggested that it was a subject which only became relevant once patients had received the highest quality palliative care, which as is suggested above, was said to reduce circumstances in which people would request a premature end to their lives:

*“I don’t think that palliative care is an alternative to the right to die, but I don’t think that the right to die should be implemented, before there’s universal access to palliative care, because we find, and there’s a lot of research which says that people who have access to palliative care, I think in Oregon, I think it was a study which said that 47% of people who then had palliative care decided that they didn’t want to die anymore.” Physician, Africa (P07)*

This evidence is contestable, as reports from Oregon also suggest that there have been increased requests for an assisted death from patients receiving palliative care compared to those who are not.<sup>lxiv</sup> However it certainly seems appropriate for efforts to be made to relieve patient suffering before considerations of an assisted death.

However, although views within the sample were broadly negative towards the idea of a right to die, some participants acknowledged that there was some suffering which palliative care could not resolve. For example:

*“I think we can make an attempt to relieve all suffering, the point is finding out where that person is at and why has he got those wishes and what is, what is causing that existential suffering and seeing what we can help with, [but] there’s going to be things which are beyond us, or there are going to be things that are beyond the doctor.” Physician, Africa (P07)*

In such circumstances, one participant presented euthanasia as a stage which may follow palliative care:

*“At the moment even palliative care cannot help the person sufficiently anymore, then euthanasia comes in” Pharmacist, Europe (P01)*

This view was supported by the PPI Representative:

*“I think that palliative care should offer the opportunity to die at home, or a place of your own choosing, in comfort, at a time of your own choosing, if you find that life is just too much to bear, then the means should be provided for you to take that step. I can’t imagine anybody takes that step easily, or without a whole load of thought. People should not have to go to Switzerland to get the relief they need.... But no, I think [assisted dying] is something which should be instituted. Definitely. You have a right to self-determination. There is certainly a right to life if you want it, but I think there’s also a right to a decent death if you want it.” PPR Representative, Europe, (P11)*

It is not possible or appropriate to extrapolate the view of one public representative beyond the individual. Indeed, supportive voices for a right-to-die were often provided in a personal, rather than in a policy-related sense, however, it was suggested that a right to palliative care and a right to die were not in opposition to each other:

*“Overall I don’t think the right to palliative care is incompatible with a right to die. Personally I feel that if I were in a situation where I felt life no longer has any value that I should have the right to decide to step out, even if I can no longer actually do so myself.” Activist, North America (P12)*

This is a very sensitive issue and one which all individuals are likely to have an opinion. However, no strong reasoning was provided as to why palliative care is resistant to the right to die movement, nor

why the right to die movement has gained the most traction in countries like Canada which *do* have palliative care. Some clues as to this reasoning, however, may be perceived fears amongst participants – most notably physicians - that their personal views notwithstanding, if a right-to-die became legislated, then they would be the people who would be tasked with providing this service:

*“I don’t see, even if it were to be legalised, either in New South Wales, or anywhere, I would not see physician assisted suicide to be part of palliative care, I think that most of my colleagues here in Australia would feel that that would be very very separate. Unfortunately, if it were to be legalised, we would be exactly the persons that would be approached to be part of this process.” Physician, Australasia (P14)*

Finally, with regards to the relationship between a right to palliative care and a right to die, there were concerns regarding public perception of a link between palliative care and assisted dying. Additionally, fears were raised that the right-to-die movement is imposing undue Western influences onto settings like Asia, and moving public debate on to assisted dying, before adequate consideration of palliative care:

*“Very parallel to end of life issues, autonomy, human rights, is the increasing acceptability of euthanasia and physician assisted suicide, especially in the western countries. And the danger is that it comes down to other countries to say ‘well, if the European countries and America is taking it, it must be good, it must be the natural progression of the legal imperative of society’. So, I find that even in my country, we’ve suddenly talking about ‘let’s think about legislation about euthanasia’, without looking at the broader picture about, how are we doing with pain relief, how are we doing with addressing suffering and quality of life in palliative care, we’ve jumped straight into the fact that because the right to die stuff is happening in the UK.” Physician, Asia (P05)*

Not all participants, however, perceived discourses around a potential right to die as presenting barriers for palliative care development. In terms of advocacy, opportunities were presented for the palliative care community to engage with the increased dialogue around end of life issues which has been fostered by the right-to-die community, for the further development of palliative care:

*“I love when people are having the discussion, because it pushes people to have the discussion about palliative care, because you can’t leave the two separated. Do I think that*

*societies should be approving physician-assisted suicide or euthanasia when they don't do palliative care? No" Physician, North America (P13)*

In spite of many participants expressing negative attitudes towards a potential right-to-die, it may also be considered developmentally. That is, that in the same way that participants accepted that in developmental health systems, that prevention and curative services would be prioritised before palliative care, that once universal access to palliative care had been secured, then a right to die may follow.

It is however clear that there is a rational argument for palliative care to be considered a human rights issue. Additionally, it seems that the lobby is making gains beyond making arguments for how palliative care is applicable within existing human rights legislation, with new policies as identified in the Americas – written stating explicitly that access to palliative care should be considered a human right. However, concerns have been raised regarding the applicability of human-rights discourses in all regions of the world. In this regard, other arguments are necessary which may resonate more clearly with audiences less amenable to human rights discourse. With this in mind, attention turns to a further way in which palliative care may be 'framed', as an ethical and moral issue.

### **Provision of palliative care as a moral and ethical imperative**

All participants within the sample presented access to pain and palliative care services as a moral imperative. Indeed participants took a highly principled stance in all interviews. The following statement from the PPI Representative in this regard was representative of more broadly held views:

*"Are we supposed to really leave them to writhe in their last moments of life and undergo terrible pain and discomfort? I think anybody who expects that needs their head looking at frankly. It's an ethical problem, you cannot say, 'we're not going to give palliative care', you can't." PPI Representative, Europe (P11)*

The moral/ethical argument for palliative care emanates from normative perceptions of the global need for palliative care. That is, that whilst the suggested palliative care population is in relative terms, small compared with the global population, that the burden of suffering which they endure is disproportionate. Yet, the relatively low numbers involved, led one participant to emphasise the

achievability of addressing global palliative care need with an implied moral imperative to do so. Speaking in terms of children:

*“I think there’s an issue of numbers as well...If I’m looking at a global level, one of the arguments that we’ve started making is, ‘sure the numbers of people needing palliative care aren’t enormous...We have a number that we can actually manage, when we talk about children, 30 million is not a big number in the scope of things, it’s manageable, the international agencies could actually achieve and they would feel good about it, as well, it’s like eradicating polio...” Nurse, Africa (P06)*

In this regard, other participants placed moral responsibility upon richer nations to assist poorer ones, to help them meet the palliative care needs of their populations. That is, that globally speaking, the inequity in access to palliative care services, where richer countries enjoy greater provision of services, that this imbalance is morally unjust:

*Under the principle of mutual and shared responsibility, which is a principle of international law, that the more developed countries with money would finance, with technical assistance or whatever, whatever needs in the lower resource countries that they have, to develop their workforce and to develop their medical industries or whatever they need, not as charity, but as mutual and shared responsibility, that they would see it as a responsibility, an ethical imperative and not just to improve their bottom line, but as an ethical imperative because that’s the kind of world that we want to live in, yeah.” Activist, North America, (P02)*

This issue of inequity applies both between and within nations as was discussed within the sub-theme of ‘Inequality and inequity of access to palliative services’. The only thing to add here, is to suggest that this imbalance, often due to socioeconomic factors at both individual societal levels, may be used to add weight to moral and ethical arguments. That is that whilst people continue to suffer, due to the consequences of illness and the fact that such suffering is known to be avoidable, creates a moral imperative to do so.

The issue of child suffering was deemed to be particularly emotive amongst participants. Considerable anxiety existed however regarding how child suffering may be presented, without being exploitative. Yet due to the perceived moral intolerability of children suffering needlessly in

circumstances where there is a lack access to palliative care services, opportunities were presented for how advocacy can make gains in this regard. Here, a paediatric nurse reflects upon this:

*“I’ve always said to my more adult focussed colleagues, that ignoring children for so long has actually diluted the message, because children do have that emotional impact on people, people don’t want to think about children suffering, you know, and adult, and I always say, an adult, someone who can understand, can try to make sense out of what’s happened to them, but the tiny little child, they can’t, all they know is that they feel sick, and they’ve got pain and they can’t play with their friends, they can’t understand what is happening, and so I think that if we could just show people that children as well as adults suffer, that we would have a little bit more... even more impact in our advocacy impact.” Nurse, Africa (P06)*

In this regard, a great deal of discussion related to the ethics involved with how to demonstrate child suffering to policymakers. As mentioned in terms of story-telling, patient narratives are one way in which the existential changes which occur when going from extreme suffering, to comfort through palliative care is one strategy. Another, however, involves the use of different media, such as video and imagery. There was, however, a great deal of unease amongst participants, regarding the risks of exploitation inherent in the visual demonstration of child suffering as well as doubts as to its potential impact due to potential desensitisation in the event of over exposure:

*“If you look at the palliative care it has evolved showing lots of graphic images and people in pain and screaming and that is absolutely not good, it’s counter-productive, and we don’t want to show, to even increase vulnerability for people who are already vulnerable... I think sometimes we have used patients and used the circumstances to meet our own advocacy demands, but without any direct benefit to the people we have used, so I’m always very careful when we are using patients, if there is no direct benefit to that patient.” Activist, Africa (16)*

A key debate in this regard, it whether it is justifiable to use the image of one child who may not be helped directly by doing so, but may lead to benefits for other people who may face similar circumstances in the future. Additional questions were raised regarding where there was a difference between the use of images of adult suffering and those of children. Yet, the view that use of images of suffering was counter-productive was not universal. The PPI representative grappled with the moral validity of such this question in relation to adults:

*"We've seen some fairly horrific images in the past. There was the little girl running away from the Napalm burns, in the Vietnam war, that is regarded as one of the photos which helped stop the war, when people looked at it and decided that, you know, enough is enough and then started the Vietnam War movement. But, obviously, it would have to be with the consent of the person being depicted... I think possibly yes, I was going to say no, but I've changed my mind, I think possibly yes, and for patients to perhaps talk about their experience, if they can, as well." PPI Representative, Europe (P11)*

Furthermore, although during interview the participant rejected use of images of children in this regard, the same participant got in touch subsequently to state:

*"I've changed my mind about using images of children to draw attention to catastrophes, famines, etc. My negative reaction was a response to the increasing exploitation of children, but on consideration - it has been done already very effectively." PPI Representative, Europe (P11)*

Evidently the issue of use of images relating to suffering is a sensitive one and there was no consensus within the sample regarding the validity of doing so. Yet, such questions must be grappled with in order to increase the influence which advocacy can hope to achieve. In this regard, the risks of 'exploitation' and 'enhanced vulnerability' may come to pass, if moral arguments and emotive imagery are used without a clear purpose. It must be asked therefore, who the moral/ethical 'frame' should seek to influence?

One participant suggested that the focus should be upon national governments and it was suggested that the frame may be useful only in settings where there is little or no palliative care provision at all as well as noting that perhaps no single frame in isolation may be appropriate:

*"In countries where development is limited, prioritize the economic factor and the moral imperative, whereas in countries where already reached some development, maybe other factors become more important" Physician, South America (P15)*

It follows, that whilst ‘moral and ethical reasoning’ is considered the frame, least likely to influence policymakers, that moralistic arguments, may be best used to contribute towards this idea of ‘experiential learning’ and awareness raising.

Yet, advocates must ask themselves clear questions in this regard. What is the use of presenting national governments with moralistic arguments for palliative care, when, within developmental healthcare systems, claims for increased palliative care sit alongside the need for other interventions such as vaccination programmes? Where life expectancy remains tragically low. Would such moralistic arguments be better presented to richer nations who have both the capacity and resources to further development? Palliative advocates must consider further, which of these ‘frames’ is most likely to influence new stakeholders in palliative care and who these stakeholders may be. Moreover, with questions regarding the absence of leadership within the palliative care community, at both national and international levels, the future may lie in increased understanding of the relative place of palliative care within broader global health priorities. To consider this further, a short discussion follows.

## **Discussion**

This chapter has revealed the diverse range of challenges and opportunities to the further development of palliative care internationally reported across six thematic categories. The elicitation of the views of a wide range of experts in the field has served to identify current advocacy strategies as well opportunities for new approaches. Contained within the six themes are a wide range of diverse issues, all of which interact in complex ways to present a full picture of the global environment in which advocates are using diverse approaches and arguments, to engage a wide range of organizations and policymakers. How then can we make sense of this complexity? In order to do so, the following section discusses the overall findings of the chapter, in relation to the aims and objectives.

### **Re-defining why palliative care is needed**

A key objective of this chapter was to elicit the views of experts regarding how the presentation of the problem of lack of palliative care can be refined. It has been identified throughout this study, how policymakers are more likely to be influenced by problems which may be considered *tractable*.

That is, a clear problem is defined, a solution presented as well as the benefits which would accrue from addressing the need.<sup>lxv</sup>

In this regard, there appears to be missed opportunities concerning how the need for palliative care is conceptualised. A high level of diversity was identified regarding why there is a global need for palliative care and who this affects. Commonly, need was expressed in terms of the suffering which patients endure to a lack of palliative care, with statistics to demonstrate the level of need. However, during discussions regarding the 'broad benefits' of palliative care, potential benefits were described which are far more diverse than the 'need' or 'problem' which participants structured.

For instance, whilst increased 'community cohesion' was presented as a benefit, it was not articulated clearly if and how there is a current *lack* of community cohesion with a consequent need for palliative care. Furthermore, in terms of 'solvability', community cohesion was presented as a benefit without consideration of how this could be measured as a 'result' of palliative care. This is a circumstance which may be remedied through consideration of literature on 'health promoting palliative care' an approach which is discussed in more detail in the following chapter.<sup>lxvi</sup> In this regard, it appears that palliative care advocates are missing opportunities to maximise the value proposition which palliative care has to offer for stakeholders beyond patients. Furthermore, an ongoing tendency to present the 'need for palliative care' using disease statistics, may be considered meaningless if we accept the prominent viewpoint of participants that policymakers lack awareness and understanding of what palliative care is, why it is needed and what its benefits are.

Importantly, ongoing confusion regarding just what palliative care *is* continues to undermine any message which activists are seeking to deliver to policymakers.<sup>lxvii</sup> In this regard, it was identified how terms such as 'palliative care', 'hospice care' and 'end of life care', continue to be used interchangeably *as well* as to describe distinct approaches. In seeking to raise awareness of all stakeholders, there is a serious need for consensus and consistency on such issues.

More significantly, the term 'palliative care' continues to be used to mean describe different approaches and with regional variation. Arising from contexts such as Africa, the term was used to denote a long term intervention which is appropriate from diagnosis and aimed at improving quality of life. Conversely in regions such as Europe and North America, the term 'palliative care' was commonly used to denote an end of life intervention. This circumstance should be of real concern to the field as many of the benefits which participants described that palliative care can offer are highly dependent upon the timing of the intervention. For instance, human capital arguments appear to be

reliant upon care introduced at an early stage, whereas, arguments that palliative care ‘reduces health system costs’ are less clear if care is introduced at an early stage.<sup>lxviii</sup>

This circumstance has profound consequences for the arguments which activists can make regarding the need for, and benefits of palliative care. In studies which *have* shown the cost effectiveness of palliative care comparatively, there is a lack of clarity regarding what ‘usual care’ is and we therefore do not know if curative attempts were continued or not.<sup>lxviii</sup> Furthermore, Chapter Five identified no studies which provide evidence for increased economic productivity of patients or families following palliative care. What this means is that the two arguments are not only mutually exclusive, but are also not currently backed by firm evidence.

More fundamentally, whilst ‘lack of awareness’ of palliative care has been identified as a key barrier to development, it is of real concern that activists are not providing a clear message to policymakers. An ongoing lack of clarity regarding whether palliative care is a long-term, or end of life intervention threatens to not only reduce the clarity of the message which advocates are seeking to deliver, but to confuse advocacy targets to the point of disinterest.

#### **What are the key asks of the palliative care community?**

WHO guidance regarding key tenets of a successful advocacy strategy, suggests that when meeting with policymakers, advocates should always have clear answers to the direct questions ‘what do you want me to do?’.<sup>lxix</sup> In this regard it is of concern that participants often expressed key demands somewhat vaguely, using language such as ‘universal access to pain treatment’ and ‘universal access to palliative care’ without adequately explaining what such terms meant in reality.

In terms of access to pain treatment, a clear aim for advocates was for national governments to introduced appropriate regulations to enable access to essential pain medicines. Indeed, effective strategies were described for engagement with national governments in order to de-regulate opioid medications using a human-rights approach. Moreover, some evidence of strategic partnerships was identified, with Human Rights Watch (HRW) confronting governments with problems, whilst the International Association of Hospice and Palliative Care (IAHPC), offered technical assistance. However, in spite of the success experienced by HRW in partnering with the pharmaceutical industry to ensure appropriate regulation of opioids in Mexico, no extrapolations were made regarding how such an approach may be applied in other settings.<sup>lxx</sup> Furthermore, doubts have been cast regarding the relevance of human-rights approaches in all world settings.

Discussions regarding 'access to pain treatment' nevertheless were the most straightforward. Clear suggestions were made regarding how such access can be monitored, using indicators of opioid consumption. In this regard, it may be considered a major blow to the field, that the SDGs have not included an indicator with which to monitor access and use of pain medications. However, based upon the views of several participants, including the public-patient representative, it may be suggested that focussing upon improving access to pain relief is an appropriate strategy in circumstances which have little or no palliative care at all. This suggestion is made based upon the relative importance of pain treatment identified in relation to other elements of palliative care, as well as the tractability of the arguments which advocates are making.

Less clear was what was meant by 'universal access to palliative care'. Participants supported the statement that 'access to palliative care was a human right'. However, there was little engagement with just exactly what is meant by this, for elements of palliative care aside from access to pain treatment. This means that there was no clear articulation of what a 'minimum package' of palliative care consists of and instead 'access' is often defined loosely for instance in terms of 'availability of community-based services'.<sup>lxxi</sup> This is a key barrier for advocacy. For instance, in terms of human rights approaches, would a person's human rights be violated if they received all elements of palliative care aside from 'spiritual care'? This is a somewhat trite statement, but it does reflect the fact that most participants were unable to articulate just what was meant by 'access to palliative care'.

What is more, no suggestions were made for what a globally collected indicator for palliative care may be. Instead, it was stated that 'access to palliative care' should be measured in terms of 'access to pain medication'. This situation is of real concern as palliative care seeks to ensure its place within Universal Health Coverage and additionally limits the potential for engagement with health insurance companies in private healthcare systems. If palliative care activists are unable to articulate just what access to palliative care *means*, then this further reduces the tractability of the arguments which they can make to policymakers.

Indeed, just one participant described with any clarity what 'access to palliative' care may consist of, in terms of "access to generalised care" [*Physician, Africa (P06)*]. A key problem with this articulation, however, is that in many world settings, doctors are scarce and patients may only ever be seen by a nurse. In this regard, innovative suggestions based upon a model of practice in Uganda suggested

that nurses should be empowered in order to prescribe and deliver pain medications. Achieving this was said feasible, as nurse training was said to be cheaper and take less time than to train palliative care doctors. Furthermore, an evaluation of the Ugandan approach to opioid availability has been evaluated positively and recommended as a model for the rest of Sub-Saharan Africa.<sup>lxxii</sup> Based upon the findings of Chapter Six, it may be suggested further, that the model may be appropriate for other 'similar' settings.

We may understand 'access to generalised care' as a call for palliative care to represent an important element of undergraduate medical curricula. This may be considered a 'key ask' of the palliative care community. Calls for increased education are consistent with commitments contained the WHA Palliative Care Resolution for national strategies to be developed for palliative care, with education a key component of this.<sup>lvi</sup> Moreover, increased palliative care education at all levels is an important element of suggestions regarding how the existing culture of medicine can be challenged.

Yet, although the WHA was passed unanimously, the overwhelming view of participants and supported by broader literature, was that national policymakers continue to have low awareness of palliative care.<sup>lxxiii</sup> Moreover, as was identified in Chapter Six, countries which have low levels of palliative care development, also face serious other developmental challenges, to be faced with limited budgets. Therefore, whilst many participants supported a reallocation of resources for palliative care, in such settings this would mean diverting resources away from other areas of pressing need. What is more, in countries where coverage of doctors is low, there appear to be fewer opportunities to make savings based upon reduction of 'futile treatment'. Furthermore, any initiatives to empower nurses to provide pain relief, must be considered in the context of the existing pressures upon community health nurses, who are known to have high workload, with studies already reporting burnout amongst nurses due to their existing workloads.<sup>lxxiv</sup>

Therefore the development of national strategies for palliative care may be considered in terms of attracting new sources of funding. Global funding agencies such as the Global Fund disburse funding for health based upon national health strategies. Accordingly in low and middle income countries, the key importance of developing national strategies for palliative care may be considered in terms of attracting new sources of funding which once again shows the complex interaction between national and global level forces.

### **Framing palliative care; who needs to be influenced and how?**

It was identified in Chapters Two and Three how palliative care has predominantly received policy attention from normative global agencies such as the WHO. In this regard it was shown how such organizations are amenable to human rights arguments for palliative care. However, due to the lack of funding available from such organizations it was suggested that new ways of presenting the importance of palliative care were necessary in order to reach out to new stakeholders and funders. Within Theme Six, 'framing palliative care' a wide range of arguments for the further roll-out of palliative care were identified. Broadly speaking, such frames may be summarised in terms of palliative care being; an international development issue, a human rights issue and a moral and ethical imperative. Additionally, a wide range of targets for advocacy were identified, from individuals such as Ministers of Health, the general public, National governments and global level actors, for instance USAID. Less clearly articulated was to which advocacy targets, each 'frame' should be targeted to and on this basis, some extrapolation is made here where such clarity was not provided.

Firstly, it was suggested that Ministers of Health may be key actors who are able to implement palliative care education within medical curricula. In this regard, one participant, a physician, reported an example of 'experiential learning', whereby they found themselves caring for a government officials' mother. The mother had attended several expensive private hospitals, none of which had been able to reduce her symptom burden. However, on attendance at a free palliative care service her condition was improved with the official asking '*now, if you can do this, why can't our hospitals do this?*' This serves as an example, where cognitive change has been achieved through experience. However, there remains an element of coincidence that the official came into contact with a palliative care service. This may therefore be considered a 'hopeful' advocacy approach, for which strategic planning is not possible.

Therefore, a more astute approach may be to approach such Ministers of Health, and indeed national governments, using arguments which hold benefits for health systems. For instance, it was suggested by many participants that the introduction of palliative care instead of inappropriate curative treatments would reduce overall hospital expenditure, claims supported by some national-level evidence.<sup>lxxv</sup> Moreover, there is a wide body of literature which suggests that effective palliative care can reduce unnecessary hospital admissions, particularly when care is delivered at home.<sup>lxxvi</sup> This argument also holds potential to engage private health insurance companies, however, as has

been described, it is not clear if this argument is viable in circumstances where palliative care is introduced *alongside* as opposed to instead of curative efforts.

However, in spite of the apparent potential of economic arguments to influence policymakers, they were considered by participants as being potentially counter-productive method of engaging the general public. Indeed, it was reported how in America, the presentation of palliative care as a 'cheap' intervention had led to misunderstandings regarding palliative care as a form of cost-saving 'abandonment'. This viewpoint represents broader barriers to the further roll-out of palliative care which has often been mis-associated with 'abandonment'.<sup>lxxvii</sup>

In this regard, participants emphasised that moral and ethical arguments may be a more effective way of engaging public interest in palliative care. Use of story-telling which describes patient experiences moving away from suffering towards improved quality of life was said to be a key way of raising awareness.<sup>lxxviii</sup> Moreover, the importance of engaging the media to deliver such messages was stated. Examples included, radio broadcasts discussing palliative care and the use of videos adverts, delivered by celebrities, which stressed the need and value of palliative care.

Yet, gaining public support for palliative care is but one challenge to the palliative care community and there remains an urgent need for engagement from organizations such as the World Bank who have the capacity to fund further development. It has been argued throughout this thesis, that such organizations prioritise 'human capital' over 'human rights'. In this regard, participants made arguments that human capital could be increased for patients, families and health-workers. It was suggested that in some settings, reduced symptom burden may allow patients to return to work for a period of time. Additionally, reduced symptom burden was said to relieve the burden on carers which may allow *them* to continue economic productivity. Lastly, 'burn-out' of hospital staff was identified as an issue, whereby, the act of treating patients with high symptom burdens leads to psychological distress and consequent absence from work. Palliative care, it was suggested, can lead to more positive experiences of treating people with serious illness for health workers, with consequent reduced psychological distress. However, such arguments must be used with caution, given that one study of burnout in palliative found that levels were no lower than those seen in other contexts.<sup>lxxix</sup>

In this regard, theoretically there exist diverse and convincing 'frames' within which palliative care can be presented, though there must be ongoing concerns regarding the extent to which they are evidence-based. What is more, in spite of the range of 'frames' which are available to advocates,

participants retained views that palliative care activists were not doing enough. One participant indeed reflected upon the unhelpfulness of simplistic approaches which seek simply to demand that governments should introduce palliative care. Instead, it was suggested that specific arguments were necessary for specific issues, for instance, examining palliative care policy recommendations in relation to government financing and 'making a case for that'. Or in terms of access to medicines:

*If we want to control pain and only doctors can prescribe pain medication because it's an opioid, and 60% of the Africans, or people having palliative care may never see a Doctor, so it means you're automatically excluding 60% of patients from accessing pain medication. Because the person seeing them cannot prescribe. So make the case about task shifting"*  
*Activist, Africa (P16)*

In many ways, owing to the vast range of challenges which of palliative care faces, it is inappropriate to criticise any advocacy efforts identified within this chapter aimed at further development of palliative care. To do so would be to undermine the strongly principled viewpoints which all participants adopted, with all efforts aiming to resource the burden of suffering faced by people with serious and life limiting illnesses. Yet, in spite of the varied ways in which the need for palliative care can be presented and the benefits which can accrue from its introduction, activists and researchers must ensure that such arguments move beyond anecdotal accounts and are backed by firm evidence.

In this regard what has been evident throughout this chapter is that there remain serious challenges to the further development of palliative care. On this basis, this chapter concludes with a short discussion of these challenges as well as identification of new partnerships which may hold the potential to overcome them.

### **Key challenges and the need to forge new partnerships**

It is suggested that partnerships in international development hold the potential to enhance outcomes and also to produce synergistic rewards for all partners concerned.<sup>lxxx</sup> Moreover it is suggested that partnerships can contribute to the sustainability of institutions involved with them. Therefore consideration of the limited partnerships which the palliative care community has forged identified within this chapter may be understood as revealing the fragility of palliative care development. Questions regarding the sustainability of development models which have relied

largely upon ‘pioneers’ are echoed by the temporal partnerships which palliative care has formed with funders such as the Open Society Foundation, who provide short term grants.

In this regard, funding remains a key challenge for the field in both low and income settings. Yet in spite of the prevalence with which arguments for a ‘public health approach’ were used to further development, it was somewhat surprising, that participants did not give a clear ‘frame’ as to why palliative care may be considered a ‘public health issue’. Responses which emphasised the uneven burden of suffering, which the relatively small palliative care populations endure may be extrapolated to be considered a public health issue. There is some recognition that the need for palliative care is a public health issue in particular by the WHO and palliative care organizations.<sup>lxxxix</sup> However, participants identified that broader public health community has been identified as having paid little attention to palliative care. This may be as ‘public health’ itself is a contested term palliative care does not appear to fit clearly into the somewhat nebulous definitions of just what a ‘public health issue’ is.<sup>lxxxix</sup> The WHO defines public health as:

All organized measures (whether public or private) to prevent disease, promote health, and prolong life among the population as a whole. Its activities aim to provide conditions in which people can be healthy and focus on entire populations, not on individual patients or diseases [WHO, 2015].<sup>lxxxix</sup>

In this regard, palliative care is once more left battling to make an argument for how palliative care *can* help prevent disease and be included as an inherent part of health promotion as above. This definition is broad enough to make such arguments, however, as has had to be done with existing international human rights legislation, palliative care must fight for its place within public health discourses.

Palliative care activists must therefore consider reaching out to new partners in order to form synergistic relationships. Accordingly one participant acknowledged the potential role for palliative care in disease prevention, but lamented that the community was not currently reaching out to new partners to insert itself into broader discourses:

*“Maternal Child Health, everybody is talking about it, keeping mothers alive, keeping mothers and babies alive, there is an indicator for that, everybody is talking about it. 70% of the funding is going to MNCH even in countries and from USAID, you know. So it’s really*

*learning from those opportunities, but also, for us as palliative care people, thinking about how, what is our contribution to the wider debate? What is the contribution of palliative care to saving mothers, what is the contribution of palliative care to saving HIV? You know?"*  
*Activist, Africa (P16)*

In this regard, it was acknowledged that the broad public health community is not engaged with palliative care at global level. Moreover, activists appear to be too dismissive of serious public health issues which *do* arise regarding opioid availability. Whilst it is clear that pain medicines should be available, it is too simplistic to deem barriers such as 'fear of opioids' as being down to lack of awareness. One participant acknowledged that there were *two* public health concerns regarding opioids, both under *and* over availability of opiates, with addiction to such medicines a growing problem in settings such as the United States.<sup>lxxxiv</sup> However, the palliative care community must reach out to address such concerns rather simply dismiss them as 'fear', based upon 'lack of awareness'.

Palliative care must therefore attempt to move forwards and place itself within the wider health governance system. Elicitation of new partners such as maternal health and HIV as identified above, would raise awareness, allow palliative care professionals to conduct less usual roles such as identification of at-risk populations and disease prevention, whilst making gains towards their own bottom line. Additionally, re-consideration should be given regarding how palliative care can forge partnerships with private sector actors. That is, given the increasing prevalence of private health systems and public-private partnerships in global health, it is not appropriate to dismiss private actors as being irrelevant to palliative care.<sup>lxxxv</sup>

Additionally, whilst participants situated palliative care firmly with the SDG of UHC, further opportunities remain for the community to reach out and contribute to other goals. For instance, inequality of access to pain treatment was identified as a serious inequality which may resonate with actors within SDG10, to reduce inequality within and between nations.<sup>lxxxvi</sup>

Perhaps more significantly, what does palliative care have to say about Goal 1 of 'No Poverty'? It is well established that serious illness can leave families vulnerable to the 'poverty trap' and participants suggested that palliative care can reduce, if not eliminate, household expenditure on healthcare. Yet, in spite of the wide range of arguments which can be made for palliative care across

multiple domains, and the benefits which accrue for a wide range of stakeholders at all levels, it appears that current advocacy approaches are not yet maximising this value proposition.

## Conclusion

This broad chapter has revealed a number of key issues in terms of how palliative care is developing around the world. It has raised doubts in terms of the sustainability of development models, which have seen key champions and pioneers driving models of care which are reliant upon short term funding streams from charitable fundraising and philanthropy.

Findings within the chapter represent a significant contribution to understanding the current place of palliative care at both global and national levels. For instance, it has been suggested, that in the absence of a clear vision of what a 'basic package' of palliative care consists of, is undermining advocates efforts to integrate palliative care into global health policies such as Universal Health Coverage. What's more, due to the broad lack of engagement with issues relating to how palliative care may be better integrated into private health systems, it has been argued that the absence 'key asks' in terms of what a basic level of palliative care consists of, further limits the potential for advocates to engage with private healthcare providers. In this regard, access to pain treatment has been shown to be both the most pressing issue in terms of development, as well as the most clearly defined problem, with tractable solutions.

With regards to how advocacy can help move the field forwards from the current rate of development, which has been shown in Chapter Six to be consistent with broader international development processes, several different ways of making arguments for further roll-out of palliative care have been identified. Different 'frames' including economic arguments, moral/ethical and human rights arguments have been presented. The value of each argument has been shown to be highly dependent upon the *timing* of palliative care as an intervention. This situation is highly problematic for the field, which continues to operate with differing perceptions and understandings of what palliative care is and from when it should be provided. The tension regarding whether the key message of palliative care should focus upon improved quality of life, for people living with serious illnesses, or upon end of life care and quality of death, goes to the heart of tensions within the palliative care movement, which remains conflicted, regarding the direction of the field. Although there was no suggestion that palliative care is not able to ensure *both* quality of life and

quality of death, advocates appeared split, regarding the gains which can be made in terms of public attitudes and policy when the key outcome is presented as quality of death. The counter to this was said to be to focus upon quality of life and “let the issue of death worry about itself [Physician, Asia (P05)].”

In terms of how global policies are influencing the development of the field, it has become evident that palliative care continues to operate on the margins of global health discourses. The WHA Resolution in 2014 may be considered the first truly global palliative care policy and presents great opportunities for the field to develop. Additionally, although no indicator for palliative care was included within the SDGs, it has been shown how palliative care has benefits for stakeholder patients and families as the unit of care and can contribute to the overall strength of health systems. In this regard, the field retains great potential to maximise opportunities to benefit from the huge amount of resources which will be directed towards meeting the SDGs. On this basis, the final chapter of this thesis reviews the key findings of the study and identifies what more is needed in order for the field to move forwards.

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## Conclusion

### How Can Current Rates of Palliative Care Development be Accelerated?

#### Introduction

This thesis set out to contribute to understanding the international development of palliative care in the context of broader global health discourses and policies. More specifically, it sought to answer the research question:

*Can the global development of palliative care be furthered through increased understanding of global policymaking processes and the presentation of palliative care as an international development issue?*

In so doing, the thesis has made a number of important contributions. Firstly understanding of palliative care has been significantly increased through the application of a Global Social Policy (GSP) approach to place the development of the field within the broader global health landscape [Chapter Three].<sup>i</sup> Secondly, the application of a multiple-methods approach has demonstrated that in spite of a significant global need for palliative care, the type and quantity of available evidence for palliative care in the international context continues to limit the tools with which advocates can engage with both national and global policymakers [Chapter Five]. This is important, as the model of development which palliative care has followed has shown to be fragile. That is, that development largely has been driven by motivated individuals and individual organizations providing short-term funding streams. Therefore, there remains an urgent need for structural change within healthcare systems, to ensure that access to services is both increased and sustainable.

The passing of a World Health Assembly (WHA) Resolution for palliative care in 2014 represented new attention for palliative care from global health actors.<sup>ii</sup> However, as indicated in Chapter Three, there is no enforcement mechanism for the Resolution. As a result, serious concerns remain regarding what such normative guidance can achieve. The Resolution places financial responsibility to implement palliative care upon national governments, many of which already face serious budget pressures and broader, more commonly understood development challenges.

In order to consider how the field can move forward, the views of international experts in the field of palliative care were elicited (Chapter Seven). It was revealed how palliative care holds the potential for wide-ranging benefits: for patients, families/carers, communities and health systems.

However, significant divergence of understanding regarding what palliative care is, even within the field, means that many claims made by study participants are not backed by firm evidence. For example, instances where palliative care patients have been able to return to work were reported anecdotally but is an argument which appears reliant upon palliative care being introduced at an early stage of illness. Furthermore, no evidence is known to demonstrate such effects of treatment (see Chapter Seven). Moreover, an ongoing lack of clarity regarding just what palliative care *is* has been identified as a key limiter on the fields' development and a contributing factor to ongoing practices of medical practitioners who maintain a highly technical curative approach to medicine at all stages of illness and do not provide appropriate care focussed on comfort and quality of life.

The increased understanding provided by this study regarding how national and global level forces interact has identified significant opportunities for palliative care to make gains as the world sets its sights on achieving Universal Health Coverage (UHC). This concluding chapter reviews the main contributions of this thesis and draws out several key learning points for different types of stakeholders: practitioners, researchers, policymakers and advocates in terms of how to hasten palliative care development.

Chapter One presented an overview of the main arguments and method of the thesis. This chapter therefore does not seek to do this, but rather aims to expand upon the key arguments of the thesis relating the findings within and between the different chapters. Unique insights and contributions are drawn out with regards to how reconceptualization of palliative care as an international development issue, may serve to hasten development.

## **Synthesis of Research Findings**

Chapter Two identified how existing conceptualisations of the need for palliative care are based upon the unalleviated suffering of patients and families, which arises from lack of access to pain treatment and palliative care. However, by drawing upon the 'broad-benefits' of palliative care expressed by study participants in Chapter Seven, this need may be considered far more broadly. For instance, it has been uncovered that overly 'technical' approaches to medicine which proceed with aggressive and expensive treatments aimed at cure 'at all costs', may harm patients as well as threatening the very sustainability of health systems.<sup>iii</sup> Therefore, the 'need' for palliative care is extended as it has been presented as an approach which can both alleviate patient suffering as well as reducing costs to health systems. This finding is backed by a wide range of evidence, predominantly from Europe and North America<sup>iv</sup> However, one study in South Africa, found that

palliative care outreach teams were less costly than hospital-based palliative care, the authors concluding that community based services may be cost-beneficial.<sup>v</sup> Additionally, study participants suggested that patients and families are often forced to give up work due to the negative effects of illness. Therefore the 'need' for palliative care may be understood in terms of remediation of a circumstance which sees people leaving the workforce due to high symptom burden, and /or caregiving.

Chapter Two also identified that existing narratives of palliative care development have focussed upon national-level processes, attributing a key-role to 'pioneers', grass-roots movements and government level leadership.<sup>vi</sup> In many ways, this viewpoint has been corroborated throughout the study, with such processes characterised as 'international lesson learning', whereby 'transfer agents' have spread practices of palliative care directly to other contexts.<sup>lxxi</sup> Further examples of policy transfer were identified during interviews in Chapter Seven, for instance one participant from the study, studied in the United States and subsequently established the first hospice in a country in South America.

However, in spite of these dynamic processes driven by individuals, Chapter Six demonstrated that levels of palliative care development within nations were highly consistent with broader development levels within countries in all settings. What this suggests, is that allied to dynamic personalities driving development, that palliative care becomes integrated within health systems over time, alongside other areas of development and that 'similar' countries (in development terms) have implemented palliative care to similar levels.

This finding urges further attention to be paid to instances in which 'model services' have developed palliative care, over and above what may be expected based upon their broader developmental context. For instance, the example of Hospice Uganda which pioneered a model to increase access to pain treatment by empowering nurses to prescribe and administer pain medicines.<sup>vii</sup> This model was found to have had some success in Uganda more broadly, in particular with regards to increasing access in rural communities. Attention must therefore be drawn to Uganda's inclusion of care within National Strategic Health Plans, which led to laws making morphine freely available and allowed nurses to prescribe.<sup>viii</sup> Such an approach appears to be a real opportunity from which other countries may learn, particularly in similar developmental contexts, where many people go through their lives without ever seeing a doctor and have access only to community based nurse-led health services. Indeed, there is some evidence that this policy may be being transferred to neighbouring countries, with The Nursing Council of Kenya, in conjunction with the Kenya Hospices and Palliative

Care Association (KEHPCA), currently advocating for the adoption of this approach in Kenya - a country which has “one nurse for every 4000 people as compared to one doctor for every 18,000 people [2015].”<sup>x</sup>

However, the potential for roll-out of this model must be seen in the context of nurses’ existing workloads and whether they have the capacity to take on additional roles. Furthermore, in countries such as the UK, nurse-prescribing was opposed by doctors citing safety fears relating to people without formal medical training prescribing medicines.<sup>x</sup> Therefore, it is not known the extent to which the empowerment of nurses to prescribe in other settings would be acceptable to the broader medical establishment.

Yet, despite the acclaim which Uganda has been given as a model of care for Africa, in Chapter Seven one study participant raised concerns regarding the sustainability of the development model. In spite of the WPCA study which credited Uganda with ‘full integration of palliative care into the health system’<sup>vi</sup> it was reported that “*the work is being more sustained by grants, there really isn’t any government funding [Activist, Africa (P16)].*” This reflects a broader picture which has been identified: that many services which have developed in all income settings (eg. Uganda and the United States) have been found to be reliant upon short-term funding streams from charitable and philanthropic organizations, revealing the fragility of the development model of palliative care has followed. Furthermore, the ‘pioneer-led’ models of development which have been identified raised issues regarding succession, in terms of, what happens when the pioneers move on?

In many ways this circumstance is reflective of broader issues in global health development. A major criticism of the Millennium Development Goal (MDG) era was that a focus upon the eradication of specific diseases, led to targeted interventions and projects at the expense of overall health system improvement.<sup>xi</sup> As global attention switches towards the attainment of Universal Health Coverage (UHC) the need for national policies to situate palliative care within health systems becomes ever more urgent. Yet, it is known that many existing palliative care services operate outside of the formal health system with their own organizational autonomy.<sup>xii</sup> This means that there are risks that current palliative care funding models of service-specific financing may continue, with palliative care consequentially not incorporated as part of broader national health strategies and funding streams.

This finding that palliative care continues to operate largely outside of formal health systems and budgets, means that the optimism surrounding the WHA must be tempered with caution.<sup>i</sup> The Resolution places the financial obligation for the integration of palliative care firmly on national governments, a suggestion broadly supported by study participants (Chapter Seven). Yet, the

demonstrated association between palliative care and broader processes of development [Chapter Six] shows that countries which have not developed services to a high level, face serious challenges to healthcare delivery. What this means is that in countries where life expectancy and other health indicators are low that governments may be being asked to reallocate resources away from other underdeveloped, yet essential, health services towards palliative care delivery.<sup>xiii</sup> Such concerns sit alongside an international trend towards the private delivery of healthcare which raises further questions regarding where resources may be reallocated from.<sup>i</sup>

In this regard, many study participants suggested that palliative care ‘pays for itself’ in terms of reducing costs related to futile treatment, which could be spent upon palliative care services. However, conflicting evidence exists with which to both support and challenge such claims. For example, a systematic review of the cost and cost-effectiveness of palliative care in relation to ‘usual care’ reported contradictory findings. Palliative care was associated with reduced hospital admissions (and therefore costs) when compared with usual care for patients in the last month of life. However, no difference was detected for people receiving care for 120 days or over.<sup>xiv</sup> This raises doubts regarding claims that palliative care can ‘reduce costs’ to health systems when delivered concurrently with active treatment for a prolonged period. Furthermore, this circumstance underlines that distinct challenges exist in different world settings. Whilst there is some evidence to show that palliative care is associated with reduced hospital costs, in some settings (particularly low to middle income countries), people with serious illness may never even see a doctor therefore there are no associated costs of treatment to be reduced or reallocated.<sup>xv</sup> In such circumstances, new sources of funding for palliative care would certainly be required.

In many ways however, this underlines the need for the implementation of the Resolution in terms of the development of national strategies for palliative care. Expressed viewpoints that *governments* must find the funds for palliative care belies the fact that a high amount of health care funding comes from global level funding agencies. Such funders may provide funds for palliative care if included within national health strategies. That is, since the Paris Declaration and Accra Agenda for Action on aid effectiveness, the donor community has sought to back projects which are aligned to *national* health priorities.<sup>xvi</sup> For instance, funding agencies such as The Global Fund to Fight AIDS, Tuberculosis and Malaria –profess to make funding decisions “informed by the specific needs and characteristics of each country [2015]”.<sup>xvii</sup>

However, in spite of this political commitment to divert aid towards national priorities, studies have shown that multilateral funders continue to fund development in line with their own organizational

objectives. For instance, in Cambodia, a review of donor funding found that projects were funded which “correspond to the needs of the particular agency [eg multilateral banks], but not to those defined by the Cambodian government [2009].”<sup>xviii</sup>

This circumstance is consistent with a broad argument of this thesis, that activists must use targeted arguments for the promotion of palliative care to engage with different actors [Chapters Three, Five and Seven]. For instance, ‘framing’ palliative care as an issue of human capital, as opposed to human rights, has been argued to hold potential to gain influence with funders such as the World Bank as it is consistent with their broader developmental priorities.<sup>xix</sup> In this regard, study participants suggested that through the early delivery of palliative care and effective symptom management that patients and carers would be able to continue contributing economically to society for longer periods and consequently increase household resilience.<sup>xx</sup> Yet the findings from Chapter Five cast doubt upon whether researchers are currently equipping advocates with sufficient evidence to back such claims. For instance, no papers were identified which made a link between palliative care and extension of working lives. Similarly, although researchers have reported cost reduction to health systems through the delivery of palliative care, papers included in the systematic review did not make clear whether palliative care was introduced alongside, or instead of curative efforts.

This reveals a known, but ongoing key tension within the field of palliative care. Is palliative care an end of life intervention or one which should be delivered upon diagnosis of serious illness? In practice, this distinction may not be so clear cut, with researchers reporting on best practice with regards to the ‘transition’ from curative to palliative care.<sup>xxi</sup> However, whether palliative care is a long or short term intervention has serious consequences in terms of ‘frames’ which advocates may be able to use. Furthermore, failure to use terms and definitions consistently, threatens to undermine efforts of advocates to ‘raise awareness’ of palliative care.

What is meant by this, is that global funders have been shown to be more likely to engage with social activists, if they present a serious area of neglect, or ‘problem’, followed by a ‘solution’ showing the problem’s tractability and the benefits which would result from addressing it.<sup>xxii</sup> In this regard, this study has enlightened how the ‘problem’ of lack of palliative care can be presented. Moreover, a wide range of benefits which accrue from its introduction have been reported. What is less clear, however, is how ‘palliative care’ is the solution.

By which it is meant, that given the lack of clarity regarding just what palliative care *is*, it becomes almost impossible to describe what is meant by access to it and therefore the overall coherence of the advocacy message is reduced.<sup>xxiii</sup> Moreover, if there is no single definition of ‘access to palliative

care', then how can it be measured? This is of serious concern and risks palliative care being relegated to a low priority within the Sustainable Development Goal (SDG) to achieve UHC. Furthermore, the failure to articulate a 'minimum package' of palliative care, risks a failure to engage with health insurance companies, the only significant private actors who have been identified whose interests coalesce with those of palliative care in terms of decreased length of hospital stay.

In this regard, it was argued in Chapter Seven that advocacy should focus upon the most *tractable* argument for palliative care, that of access to pain relief. There was support from the public-patient representative amongst other participants, that access to pain relief was the most pressing challenge to the field. Moreover, suggestions were made regarding how access could be measured in terms of morphine consumption. What this means is that advocates are able to identify a problem (physical pain and its consequences), the solution (pain medication) and the benefits which accrue from addressing the problem (improved quality of life and maintenance of function). In spite of the complexities relating to how access can be secured, in terms of increasing education for nurses and physicians to prescribe, appropriate regulations etc. pain relief does appear to be the most straightforward way in which the field can make gains within global health development. This viewpoint is strengthened given that study participants were able to describe pain as a 'universal experience', whereas there was no such clarity regarding the consequences which occur in the absence of other elements of palliative care such as spiritual support. One reason for this may be that 'spiritual care' itself is a contested term and there is ongoing debate regarding the concept of spirituality and its relationship to religion.<sup>xxiv</sup>

Yet, as was reported in Chapter Seven, there was some unwillingness amongst participants to delineate the different elements of palliative care, valuing them of equal importance. The promotion of pain relief is not to dismiss other elements of palliative care. However it has been shown in varied ways throughout the study that within a global context of limited resources for health care, that policy are determined through processes of prioritisation.<sup>i</sup> Therefore, in terms of advocacy, failure to delineate elements into their component parts in order to make clear arguments to policymakers, risks palliative care being overlooked altogether.

However, in terms of both pain treatment and palliative care, many of the 'frames' and the benefits of increased access which were presented by participants continue to be undermined by a lack of evidence. Use of speculative economic 'frames' may ultimately prove harmful and researchers should aim to equip advocates with robust evidence around which advocacy approaches can be based.<sup>xxv</sup> There must therefore, be closer links between research and advocacy to determine how

each of these should inform practice. Indeed, palliative care activists may seek to look outside the field to see how the interaction of advocates and researchers has led to policy prioritisation of other health issues. For example in South America researchers uncovered evidence of high maternal mortality which led to advocates being able to confront policymakers with evidence of the problem and a subsequent policy response.<sup>xxvi</sup> However, before considering the key implications for researchers and policy advocates, it is first appropriate to consider the short and long term implications of this study for medical and palliative care practice.

## **Implications for practice**

As this was a high-level study, which primarily has examined global level policies and processes, the major issues identified predominantly relate to future research and policy priorities. Yet, mainly drawn from data gathered during interviews, several important implications have been identified primarily in terms of organization of palliative care services.

As described in Chapter Seven, study participants held divergent views regarding the divisibility of different elements of palliative care. Yet with support from the public-patient representative, several participants suggested that improving access to pain services should be a priority for developmental health systems – over and above other elements such as emotional support. In this regard, evidence from Kenya suggests that, from a sample of 201 patients, 45.8% ranked ‘being in pain’ as the most concerning symptom at the end of life.<sup>xxvii</sup> However, access to pain medication has been shown to be limited by a combination of regulatory restrictions and lack of practitioner knowledge regarding how to adequately manage pain.

There is an urgent need for increased education in pain management over and above other elements of palliative care. This suggestion however, must be viewed developmentally, that is, that if all elements of palliative care cannot be introduced concurrently, then it is rational to designate feasible short-term goals. There is therefore no implication that other elements such as ‘emotional support’ are unimportant. Instead, it is likely that there is significant regional variation in this regard and that a more holistic approach to palliative care may be more feasible in circumstances which have adequately developed pain treatment services. Yet, it should be noted that one study identified within Chapter Five, conducted across seven European Countries, also found a patient-expressed preference for pain to be relieved over and above other symptoms.<sup>xxviii</sup>

A further implication for practice regards how to increase palliative care education amongst healthcare professionals. In this regard, several initiatives were identified in Chapter Seven regarding

international educational programmes, each with a different approach. Firstly, instances were identified of western medics delivering 'sensitisation' training in countries where palliative care has not developed. Such endeavours were presented thoughtfully, in the sense that whilst it is appropriate to raise awareness of the need for services such as pain treatment, it is less so if curricula advocate for the use of medicines which are not available to course recipients. In circumstances where awareness of care is limited or non-existent, such outreach efforts are needed in order to facilitate palliative care as an aspect of healthcare need. However, there are associated risks of short-termism and even for educators to make an overall negative contribution through the delivery of inappropriate 'lessons'.<sup>xxxix</sup> The benefits of such initiatives for palliative care have been noted by researchers, although there has been little or no evaluation of their impact in terms of patient care.<sup>xxx</sup>

Secondly, as referred to above, doctors in countries which have little or no palliative care are travelling internationally to receive education which they are then able to apply to their own setting and disseminate information to colleagues. High value was attributed to such efforts within Chapter Seven. However, once more there are issues regarding the appropriateness of transferring certain lessons. That is, there may be associated dangers in terms of expectation-raising, if health professionals are taught to use treatments and technologies and are then not able to apply them in their home-setting due to lack of availability. Moreover this approach is consistent with narratives which placed individuals, or 'pioneers' at the centre of development efforts. As has been identified, although individuals are able to achieve a great deal in terms of development, there are associated dangers of this approach in terms of its sustainability.

Third, one example was identified where a European university was working with an Indian hospice to offer a distance-learning, accredited diploma in palliative care. This initiative is funded by UK through the Commonwealth Scholarships project which aims to further international development in Commonwealth countries through education.<sup>xxxix</sup> This arrangement is consistent with views expressed by participants in Chapter Seven that richer countries have a responsibility to contribute towards the development of palliative care in other world settings.

Lastly, a key change to practice suggested, is that nurses should be trained to provide palliative care and empowered to prescribe pain medications as discussed above. A less usual suggestion was made by one participant regarding the role of pharmacists in the provision of pain medication, particularly within private health systems.<sup>xxxii</sup> Responding to the dangers within private systems of doctors being placed under pressure to prescribe expensive medications equally appropriate cheaper alternatives

were available it was suggested that *“one of the roles of a pharmacist is to separate the interest in what is prescribed, from the profits [Pharmacist, Europe (P01).”* In spite of this, no evidence was identified in Chapter Five regarding the role of pharmacists. Nor did any other participants identify the key role which pharmacists may be able to play in facilitating safe supply of strong medicines in terms of ensuring sufficient supply whilst restricting over use, an issue which is expanded upon in the following section regarding future research opportunities.

More usually, allusions which study participants made to what represents good palliative care practice reflected issues which are already well known to the field and do not bear repeating here, for example the suggestion that the unit of care should be both patients and families.<sup>xxxiii</sup> Specifically, it is well established that palliative care should be patient-centred and allow patients and families to determine their own goals of care. Furthermore, no participants identified instances where palliative care practitioners were acting inappropriately with a consequent need for new approaches. In this regard, suggested changes to practice were identified more for the broader medical discipline, mainly relating to an unrealistic pursuit of cure without acceptance that there is a ‘tipping point’ during illness when palliation becomes more appropriate.<sup>liv</sup>

Researchers may have a role to play in providing evidence regarding when this ‘tipping point’ may be. However, the need for researcher to equip advocates with policy-relevant evidence extends much wider than this. The following section therefore considers key areas of priority for future research based upon the findings of the study.

## **Implications for researchers**

It was shown in Chapter Five that palliative care research capacity in low and middle income countries is low. Moreover, low levels of research output are associated with lower palliative care development. This calls to mind a quote from the late Indian Prime Minister Jawaharal Nehru, who once said that it is *“because we are a poor country, we cannot afford not to do research”*.<sup>xxxiv</sup> Whilst it has been shown that researchers from richer nations are contributing to the evidence base for palliative care in other countries, there remains an urgent need for increased evidence in all regions. Specifically, policy-relevant research is needed in terms of cost-effectiveness of palliative care interventions. This is especially important given that organizations such as the World Bank will disburse financing for the attainment of the SDGs using ‘results-based financing’.<sup>xxxv</sup>

In this regard, this section considers key opportunities for researchers to conduct studies which may equip advocates with new types of robust evidence with which they may be able to engage with national and global policymakers in line with their own priorities.

### **Outcome measurement tools to demonstrate value and benefit**

As has been demonstrated throughout this thesis, palliative care is one amongst many other health claims competing for policy attention and resources. As global health policy becomes ever more evidence-based, policymakers become ever more likely to allocate funding resources based upon cost-utility analyses.<sup>xxxvi</sup> That is, that similar to results-based financing, funding is likely to be allocated based upon cost in relation to perceived benefit to patients.

For instance, in the United Kingdom (UK), the National Institute for Health and Care Excellence (NICE) makes recommendations for which drugs and services should be funded by the National Health Services based upon 'cost per Quality Adjusted Life Year (QALY). Thresholds are set for what the national government should fund for one QALY, or additional year of perfect health.<sup>xxxvii</sup> Palliative care is not a good fit with such a cost-utility approach to funding allocation where 'perfect health' is not a feasible goal of care. It has been suggested that the lack of relevance of QALYs has led to palliative care being overlooked when funding allocations in favour of health services which have a clearer cost-benefit to patients and the health system.<sup>xxxviii</sup>

Palliative care researchers must therefore renew efforts in order to produce evidence which shows that palliative care represents value for money. One study participant indicated this need for new metrics by noting a research project currently underway, which assesses "*not just the burden of pain, but the burden of suffering [Activist, North America (P02)].*" Efforts towards the production of a Suffering Adjusted Life Year (SALY) metric, may therefore be viewed favourably. An indicator of this kind, would allow researchers to demonstrate both levels of suffering as well as consequent benefits following the introduction of pain control and palliative treatment. Yet once more, whether palliative care is a long-term or end of life intervention is of importance. That is, if palliative care is introduced only at the end of life, positive and negative health impacts may be difficult to determine, when measured in terms of weeks and months and judgements on their cost-utility become highly ethically-charged questions.<sup>xxxix</sup>

Yet, there is an urgent need to provide evidence to policymakers in terms of the economic aspects of palliative care given the relative likelihood which economic 'frames' hold to influence policymakers.<sup>xl</sup> In this regard, several studies have shown links between the onset of illness and the descent into

poverty, in both high and low income nations.<sup>xli</sup> These are negative effects of illness on families and households, which study participants in Chapter Seven suggested that palliative care could reduce. Yet, conflicting evidence exists regarding the potential for palliative care to mitigate such negative effects. For instance, it was suggested that effective palliative care can increase the human capital of patients and carers as well as contribute to poverty avoidance through reduced household expenditure on health. However, several studies have shown that palliative care can be associated with high out of pocket expenditure for families.<sup>xlii</sup> This relationship should be considered further, given the potential for ‘human capital’ arguments for palliative care. Additionally, attention should be given to claims that palliative care ‘reduces health system expenditure’ given the questions which arise when palliative care is introduced *in addition* to curative efforts as opposed to its introduction as an alternative.

Furthermore, it may be fruitful for researchers to assist advocates by equipping them with evidence of the ‘benefits’ which study participants suggested accrue from palliative care to individuals, families, communities and other stakeholders. Yet, many of the potential ‘benefits’ of palliative care described in Chapter Seven appear somewhat nebulous and were presented with little clarity regarding how they may be measured. If activists are to make arguments such as ‘improved community cohesion’ to policymakers then there must be evidence to support such claims.

In this regard, researchers should consider upscaling efforts regarding ‘health-promoting palliative care’, particularly with regard to developing robust outcome measures. This is a concept which emerged from the assertion that ‘death and loss’ should be recognised as a public health concern. It suggests that there is a need for community support and for ‘death education’ to combat the prevailing ignorance and misconceptions around death, dying and bereavement [2005]<sup>xliii</sup>.” A key challenge faced by such an approach, remains however, how to measure any potential gains. Yet, framing of palliative care in terms of health promotion allows its representation as something positive without abandonment of challenging negative attitudes towards illness and death. In this regard, researchers may again profit from looking outside of the field, to determine how other complex interventions with diverse inputs and outcomes have been evaluated.<sup>xliv</sup>

Additionally, given the importance identified within this study regarding the need for increased access to pain treatment, researchers must produce evidence which can facilitate the removal of barriers to access. For instance, ‘fear of opioids’ was a common term used by study participants. Researchers should therefore consider how to engage with such fears as opposed to dismissing them as ‘lack of awareness’. The efficacy of pain treatments such as morphine for cancer pain is well

established.<sup>xlv</sup> Less so, are studies demonstrating the models of opioid availability which protect against public health risks such as *over* availability of morphine. Moreover, given the suggestion that nurses should be empowered to prescribe and administer strong pain medicines in rural areas, studies are needed which demonstrate how medicines may be safely stored in community settings. There *are* risks of misuse of medicines such as morphine and if nurses are to be asked to become the guardians of such potentially dangerous medicines then they must not be placed in positions of vulnerability. For instance, they must be assured of their own safety in terms of the risk that community health posts may be targeted by criminal elements of society seeking to access strong medicines for misuse. Moreover, greater attention is needed as to the key role played by pharmacists as custodians of opioid medications.<sup>xlvi</sup> Several studies have shown that pharmacists have concerns regarding their legal accountability for dispensing such medications inappropriately, and locally appropriate guidance is needed as to how they can safely do so – in all world settings.<sup>xlvii</sup>

### **Considering the transferability of policies and practices**

In 2015 WHO published a report entitled ‘Tracking Universal Health Coverage’.<sup>xlviii</sup> Within this report, the term ‘palliative care’ is included, but appears just once. This underlines the scale of the challenge for the palliative care community to enmesh itself within global efforts towards UHC. Chapter Six demonstrated that countries of similar development levels have developed palliative care similarly. In this regard, evaluation of how countries such as Costa Rica have incorporated palliative care into health systems as part of universal health coverage is warranted in terms of considering the transferability of this model to ‘similar’ countries.<sup>xlix</sup> Research of this kind would help to provide lessons to other countries of similar development levels regarding how to integrate palliative care into health systems. A key element of this may be to move beyond purely financial characterisation of countries to consider demographic ‘similarities’ and the diverse challenges for the delivery of palliative care in rural and urban areas.

Relatedly, there is a current study underway entitled The Harvard Global Equity Initiative–Lancet Commission on Global Access to Pain Control and Palliative Care. This international collaboration is ongoing, however, preliminary findings have suggested that “a systematic guide and tool for drafting national pain and palliative care plans [in Lower- Middle-Income Countries] is missing [2015].”<sup>l</sup> This suggestion supports the findings of this thesis and such gaps in understanding must be addressed.

Furthermore, and as indicated above, there is an urgent need for clarity regarding what might constitute a ‘minimum package’ of palliative care. This may be defined, for example, as patients having continued access to health professionals who have received generalist palliative care training

at all levels of healthcare (Chapter Seven). Such an approach is consistent with a public health approach which has education as a cornerstone.<sup>ii</sup> In settings where palliative care has already developed to a high level, 'access' may be extended to include consultations with specialist palliative care practitioners.<sup>iii</sup> Yet, as has been argued throughout, there must be a clear definition of what constitutes 'access to palliative care' in order for researchers to conduct economic evaluations, which consider clear inputs and outcomes of palliative care.

Research of this kind may contribute towards a model upon which national health strategies can be based in order to make progress at national level and appeal to global funders in terms of the attainment of the SDGs.

### **Engagement of new health disciplines through research**

A key emphasis within the study has been upon the need for a cognitive shift, whereby healthcare professionals acknowledge that there reaches a point in illness where ongoing curative efforts may no longer be consistent with patient-goals for treatment. Yet, whilst seeking to change such practices, doctors have little or no evidence-based guidance regarding when active treatments should be ceased. For instance, one oncology article identifies a need for agreed guidelines for the cessation of chemotherapy after a limited number of regimens to allow doctors to recommend discontinuation of treatment when it becomes unlikely that the patient will be 'cured'.<sup>liii</sup> In the absence of such evidence, approaches such as 'SPIKES', provides guidance for oncologists on breaking bad news and encourages physicians to have realistic conversations with patients regarding their goals of care when the chances of curative success are remote.<sup>liv</sup> However, the extent to which such guidance is followed and why in different contexts is unknown and this approach stops short of giving evidence-based guidelines regarding *when* cessation of treatment becomes appropriate.

At times, doctors have been painted as 'uncaring' within this thesis, in terms of medics overseeing the continuation of inappropriate curative treatments to the detriment of patient wellbeing. Yet, it seems unlikely that consensus will be reached regarding a point at which active treatment may be considered 'futile'. Moreover, it has been shown throughout this thesis, there is an absence of patient-voice to demonstrate whether continuation of curative efforts is *ever* against patient wishes. That is, whether ongoing active treatment may be attributed to 'lack of awareness' of alternatives from patients as opposed to being consistent with their wishes.<sup>lv</sup> Accordingly, it may be that initiatives such as the UK AMBER care bundle, which encourages open conversation between health professionals, patients and families regarding future goals of care when there are concerns regarding

recovery, remain appropriate. However, there is a need for further evaluation of this approach to determine if it delivers sufficient benefits to patients and does not cause harm.<sup>lvi</sup>

In this regard, it has been identified throughout the study (Chapters Two, Three and Seven) that death-denying attitudes persist and that there has not yet been a societal shift which acknowledges the importance of palliative care. Researchers may therefore seek to provide more evidence that palliative care has a role to play in disease prevention and cure.<sup>lvii</sup> Most clearly, it is known that there is a lack of research regarding the potential for palliative care to identify people at high risk of mental illness, for example patients' family members and carers.<sup>lviii</sup> Emphasis upon the more publicly palatable potentials for palliative care may allow gains to be made within the broader aims of palliative care to achieve a pain-free and dignified death.

Additionally one participant suggested that palliative care for children must be at the forefront of global advocacy efforts due to their vulnerability and the 'blamelessness' of people who may be born with an incurable illness such as HIV/AIDS. Furthermore, new WHPCA guidance suggests:

Palliative care for children is based on good paediatric care which includes health promotion, prevention of infections and illnesses, immunisations, good nutrition, sanitation and management of the environment and customs that affect maternal and child health [2015].<sup>lix</sup>

Linking palliative care research to established global health priorities such as maternal and child health may facilitate its insertion into broader healthcare and development discourses. As was identified in Chapter Two, HIV/AIDS became a global health priority through its presentation as a human rights issue, an economic limiter and a national security issue.<sup>lx</sup> In this regard, there is an urgent need for palliative care researchers not only to renew efforts to provide robust evidence of effectiveness and cost-effectiveness but to think more broadly about the contribution of palliative care to public health more generally. For palliative care to be integrated into medical and nursing practice, a rational approach may be to use less confrontational language and not use terms such as 'lack of awareness' and 'uncaring', but to provide robust evidence for the relevance of palliative care to health care at all levels of delivery.

## **Implications for policy and advocacy**

To consider the implications of this study for policy and advocacy, it is first necessary to consider theoretical understanding of how policy is made. An oft-cited understanding of policymaking is

known as the Kingdon Policy Window Model which suggests that in order for policy to be formulated on a given issue, three 'streams' must align for a matter to be dealt with:

The problem stream (is the condition considered a problem?), the policy stream (are there are policy alternatives that can be implemented?), and the political stream (are politicians willing and able to make a policy change?) [Casamayou, 2003].<sup>ixi</sup>

Understanding policymaking in this manner raises serious questions for the further development of palliative care based upon the findings of this study. Firstly, the broad lack of awareness of palliative care amongst policymakers identified by study participants in Chapter Seven suggests that absence of palliative care is not universally understood as a 'problem', in spite of global recognition of the issue in terms of the WHA Resolution. More encouragingly, although this study incorporated the views of participants with a vested-interest in the further development of palliative care, no policy alternatives were identified to increased palliative care provision. That is, that there are identifiable problems raised by the absence of effective care and symptom management for patients and families and that palliative care appears to be the only rational response to such suffering. However, it follows that as palliative care has largely not been identified as a serious area of need by many national and global policymakers, there is an absence of political will to increase palliative care provision especially as the issue sits as one amongst many social problems which nations are facing as identified in Chapter Six.

In this regard, the opportunities presented by the WHA Resolution and the SDG of UHC must not be left to pass. The SDGs will be the global development priorities until 2030 and it is of great importance that these policies are translated from the global level, to national action. What is not yet known however, is if and how national-level policymakers will develop policies in order to enact the terms of the WHA Resolution and which elements of UHC will be prioritised over and above others. Additionally, even if nations include palliative care within national health strategies, the extent to which global funders will favour policies and strategies which are consistent with their own organizational mandates remains unknown.

Furthermore, whilst the WHA Resolution passed unanimously and places obligations upon national governments, participants within this study laid great emphasis upon the need for advocacy to address the 'lack of awareness' of palliative care amongst the public, national and global policymakers (see Chapter Seven). Additionally, there is a need for palliative care to form new partnerships with both global organizations as well as with other health care disciplines in order to work as advocacy coalitions and situate itself within the broader landscapes of national and global

health to ensure that policymakers adhere to the obligations set out in the WHA Resolution.<sup>lxii</sup> In order to do so, however, the ‘palliative care community’ must first establish a clear message with which to raise awareness of policymakers and other potential partners.

### **What is palliative care? An urgent need for shared understanding coherent advocacy**

Is palliative care a long-term intervention delivered from the time of diagnosis of a serious illness, or is it an approach which is introduced once curative efforts have become futile?

There is an urgent need for consensus on this issue. In spite of all study participants’ acceptance of the WHO definition of palliative care which states that palliative care is appropriate at all stages of serious illness<sup>lxiii</sup> it became clear throughout the study that there is great variety in practice. A key tenet of successful advocacy campaigns has been shown to be the delivery of a coherent message by varied actors working as advocacy coalitions.<sup>lxii</sup> Therefore, differing understandings of ‘palliative care’ must be considered a key limiter of the clarity of message which advocates are presenting to policymakers. Underpinning each of the diverse benefits of palliative care identified in Chapter Seven was a time-dependency. That is, that almost all benefits only held the likelihood to accrue if care was introduced at *either* an early or a late stage in illness. For instance, can it be said that palliative care reduces health care expenditure if it is introduced *in addition* to curative attempts? Alternatively, can the suggestion that palliative care may extend working lives be true if it is introduced only in the last days and weeks of life?

In this regard, the previously identified lack of global leadership for palliative care may be considered a major limiter for the unification of understanding. Indeed, lessons from wider literature emphasise the need for ‘strong leadership’ and ‘shared ‘visions’ in order for advocacy to achieve influence.<sup>lxiv</sup> There is, therefore an urgent need for international and regional palliative care organizations to come together and reach agreement regarding how the term ‘palliative care’ should be used. In particular, as WHO guidance suggests that a key advocacy message must be ‘clear, consistent and convincing’ as well as being reinforced by a variety of sources.<sup>lxv</sup> In this regard, the findings of this thesis should encourage the diverse international associations to work in less isolation, but to coalesce and self-conceptualise as an advocacy coalition in order to increase the likelihood of cognitively influencing policymakers.<sup>lxii</sup>

Yet the current lack of global leadership for palliative care remains a concern. Particularly as the WHO definition is broadly accepted, though understood in different ways as identified in Chapter Seven. Furthermore, whilst ‘lack of awareness’ has been identified as a major barrier for palliative

care development at all levels of governance, there is an ongoing failure to provide a consistent message, using specific terms with shared understanding. Accordingly, it is of surprise that the WHO definition of palliative care still appears within its broader section on Cancer which threatens to maintain historic misconceptions of palliative care as being for cancer patients only. Furthermore, there is an ongoing debate regarding whether the term 'palliative care' is fit for purpose at all.<sup>lxvi</sup>

Whatever the answer is to this question, there is an urgent need for consensus amongst the palliative care community so that advocacy can begin to move forwards. Failure of advocates to provide a clear message to policymakers risks 'palliative care' being overlooked in both national and global policy prioritisation.

### **Achieving global level funding; at what cost?**

Throughout this thesis, potential strategies have been identified for palliative care to present itself as an international development issue in order to attract funding from global level actors (See Chapters Two, Three, Five, Six Seven). However, 'global funding' carries both opportunities and risks in terms of how palliative care may develop in future. For example, any such funding may be short term and therefore not necessarily lead to sustainable palliative care development.<sup>lxvii</sup> Additionally, whilst the Global Fund allocates funding based on national health strategies,<sup>xviii</sup> others such as the World Bank continue to disburse funds through conditional loans, whereby funds are often allocated with conditionalities regarding how finance should be spent. Predominantly, this has meant funds diverted towards the private delivery of health care (see Chapter Three for further discussion of such issues).<sup>lxviii</sup>

Given the predominant arguments made by study participants that palliative care is a human right and that there is a moral obligation for governments to ensure access to it (see Chapter Seven), palliative care and private provision does not seem a good fit. Moreover, there are fears that any private delivery of palliative care would lead to inequalities of access, based upon ability to pay, a circumstance which has occurred in the United States.<sup>lxix</sup> Yet this is not, however, a dilemma faced solely by palliative care. If we accept that 'health' is a human right then the concept of payment for the achievement of human rights becomes an issue for all health issues.

Whether nations *should* accept funding for the private provision of palliative care is not a question for the author to answer. It serves to raise the question whether any means of further developing palliative care may be considered favourably? Chapter Seven showed how palliative care has developed to the highest levels in democratic societies. In such circumstances, it is through

democratic process that such decisions regarding any increase in private funding and delivery of service should be made. However, if the answer to this question is 'no', then what does this mean for people living within private healthcare systems? Furthermore, given the wide range of economic and societal benefits of palliative care identified in Chapter Seven, then what are the wider consequences of failing to provide palliative care beyond immediate suffering to patients?

Whatever the answer to such questions the need for arguments and evidence for palliative care as a value proposition with wider societal benefits is not diminished (Chapter Seven). Instead, if national governments, with limited resources are to find national funding streams to fund palliative care then they are even more essential.

### **Need for national palliative care policies**

That the SDGs have not incorporated an indicator to monitor progress towards the integration of palliative care into health systems does not preclude national governments from doing so. Increasing access to pain medications has been suggested throughout this thesis as a key first step towards alleviating the avoidable suffering of millions of people around the world. Yet although the challenge of ensuring universal access to pain treatment has been presented as the most pressing and tractable issue throughout the study, achievement of this aim remains complex.

Several challenges to the safe provision of effective pain treatment have been considered above, in terms of risks of over-availability and storage of medicines as well as the role of pharmacists in the supply chain. However, these issues should be considered secondarily in relation to the key challenges of formulating national policy in terms of safe, yet enabling, regulations to permit the use of opioids as well as the challenge of training medical physicians to safely and effectively deliver medicines. The WHA Resolution was significant as it identified the lack of palliative care as a 'problem'. This may be considered the first step with regards to cognitive change of policymakers and the beginning of a search for a 'solution'.<sup>lxx</sup> In this regard, it has been suggested through understanding theoretical literature regarding the process of policy transfer that it is rational for policymakers to look beyond their borders to determine how other, similar, countries have responded to this policy challenge.<sup>lxxi</sup>

In this regard, 'model services' in all world settings have been identified in the thesis to which policymakers should consider in terms of their potential relevance to their own context (Chapter Six). Much is often made of the need for palliative care services to be 'context-specific'. Such issues may, however, be considered less important with regards to the provision of pain services as 'drug

regulations' hold little relevance to context, either they permit and enable access to essential medicines for those in need of them or they do not. Additionally, owing to universal pharmacology, practically, the skills required to deliver pain treatment have little basis in context. With regards to both of these issues, the contextual challenge is to ensure the availability of affordable medicines and avoid the circumstance in India, whereby the de-regulation of opioids was reported to have led to the availability of primarily *expensive* medicines [Chapter Seven].

National deregulation of opioid medications must therefore be a key target for advocacy organizations and researchers. Whilst deregulation would only be a first step in terms of assuring access to pain treatment, without availability of essential medicines, there would be little immediate benefit of educating either doctors or nurses to prescribe them (Chapter Seven). Indeed study participants were reluctant to raise expectations of doctors regarding how they can treat pain in circumstances where medicines are not available. However, if done appropriately, such processes do appear to hold some potential to turn medical professionals into powerful actors for change through the formulation of epistemic communities, which may be able to create advocacy pressure 'from below' and lobby national governments to ensure availability of medicines.<sup>lxxii</sup>

Additionally, national governments should be encouraged to consider themselves comparatively in relation to other nations of similar development level. That is, there are opportunities for policymakers seeking to devise national palliative care policies and implement the terms of the WHA Resolution to look towards nations such as Uganda or Costa Rica who have done so in order to learn appropriate lessons. In this regard, one key way of increasing access to pain medication has been identified as the empowering of nurses to prescribe and deliver treatments (also known as task-shifting') – this was discussed in Chapter Seven of the thesis. This has been shown to be a feasible and effective way of dramatically increasing access to pain services based upon the relative lack of timing and resources required to train nurses as well as their relative prevalence in terms of coverage over doctors.<sup>vii</sup>

Yet, policymakers in all settings do not only have to look at how 'similar' countries have responded to this policy challenge: for lessons to be learned from different countries does not imply that policies have to be directly transferrable. That is, in spite of differences between nations, this does not mean that they do not face shared challenges or that lessons can't be drawn from one context and implemented in another, with appropriate amendments.<sup>lxxiii</sup> Such processes of international lesson-learning were identified in Chapter Five regarding the transferability of the Liverpool Care Pathway (LCP), a framework developed in the UK which aimed to ensure comfort at the end of life.

Although the LCP is now defunct, it may still be ‘rational’ to consider the policy response in the UK, given its top-ranking within the Economist Intelligence Unit’s Quality of Death study.<sup>lxxiv</sup> Additionally, the UK Department of Health developed an End of Life Care Strategy in 2008 which aims to promote high quality care for adults at the end of life.<sup>lxxv</sup> The strategy is said to be increasing instances where patients die in a location of their choice as well as raising the awareness of the general public regarding palliative care.<sup>lxxvi</sup> However, there are also reports that it has not had an impact in increasing equality of access to services for various ethnic groups, nor patients with a non-cancer diagnosis.<sup>lxxvii</sup>

In any event, policymakers in other settings may wish to consider what *kind* of lessons may be learned from the UK. That is, that as a ‘national palliative care policy’, the emphasis is very much upon end of life care as opposed to the delivery of care over a longer period of time. Therefore, countries seeking to develop their own national policies must decide once more, whether the primary aim of any such policy would be to ensure access to palliative care from the point of diagnosis, or at the end of life only.

### **Failure to engage with the right to die community**

Public calls for assisted dying have been growing in recent times and legislation has been introduced in countries in North America (eg Canada<sup>lxxviii</sup>) as well as in Europe (eg The Netherlands<sup>lxxix</sup>). Whether individuals have a ‘right to die’ is a complex ethical question, too broad for full consideration here. However, key concerns from opponents of such a right include fears of a ‘slippery slope’ whereby a right to die becomes a duty to die.<sup>lxxx</sup> Study participants suggested furthermore, that there were fears amongst palliative care professionals that they would be the people called upon to enact such a right, potentially against their wishes. More fundamentally, many opponents of a right to die profess that life is sacrosanct and should not be taken under any circumstances.<sup>lxxxi</sup>

What is important is that the ‘right to die movement’ is gaining increasing public acceptance in some countries and threatens to dominate discourses regarding how people should be treated and cared for at the end of life.<sup>lxxxii</sup> Furthermore, there is an uncomfortable association for the palliative care community, that the right to die movement has made the most gains in high income countries where palliative care has developed to a high level. For instance, in the United Kingdom, which is currently ranked as providing the best ‘quality of death’ in the world, people continue to travel to Switzerland in order to receive an assisted death.<sup>lxxxiii</sup> In this regard, in spite of efforts towards a ‘right to palliative care’ it has been identified throughout the study that palliative care has not yet gained the attention and support of the public.<sup>lxxxiv</sup>

Sidestepping the ethical debates regarding assisted dying<sup>lxxxv</sup>, there are potentially opportunities for palliative care to make gains by engaging with actors on both sides of the assisted dying debate. In most settings where assisted dying legislation has been introduced, there has been an associated rise in provision of palliative care. For instance, legalisation for voluntary euthanasia was introduced in Belgium in 2002 and by 2011 funding for palliative care had doubled.<sup>lxxxvi</sup> In Luxembourg, the legalisation of physician assisted dying in Luxembourg was accompanied by the designation of palliative care as a basic patient right.<sup>lxxxvi</sup> Moreover, increased engagement from the public in issues and discussions regarding how people spend the end of their lives could be used to make gains for palliative care. In this regard, it is not essential that the palliative care community either endorses or rejects assisted dying, rather advocates can remain humble regarding what palliative care can achieve and (in line with the view of an EAPC Task Force) engage in “direct and open dialogue with those within medicine and healthcare who promote euthanasia and physician-assisted suicide [2001]”.<sup>lxxxvii</sup>

## Conclusion

The significant value proposition that further roll-out of services in terms of benefits for patients, families/carers, communities and health systems means that new approaches are needed for the international development of palliative care. The absence of pain and palliative treatments is felt most keenly by patients and families who endure high degrees of suffering. Owing to this global lack of services and most significantly, pain treatments, it has been argued that increasing access to essential medicines remains the most pressing challenge to the field. The new global health priority of achieving UHC offers opportunities for palliative care to make gains. However, activists should consider the field developmentally; that is to say, to focus upon achievable change and the most immediate ‘solvable’ problems which palliative care seeks to address.

The alleviation of avoidable suffering is a moral and ethical responsibility of societies. Yet palliative care is but one of many other pressing global health needs. It has therefore been argued throughout, that there is a great need for activists to move beyond using only moralistic representations, to use different arguments for palliative care to engage with a wide range of national/global actors and health economists in particular. Moreover there remains an urgent need for wider forms of policy-relevant evidence to examine claims such as ‘increased human capital’ from palliative care as well as to demonstrate its effectiveness and cost-effectiveness, factors upon which, national and global policymakers will ultimately make funding allocations. In this regard, it is essential that increasing

access to pain treatment and palliative care are not simply viewed as national issues and must be seen as problems for the broader international development community.

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**Appendix 1.**  
**ScHARR Research Ethics Committee Approval**



Downloaded: 11/01/2016  
Approved: 27/04/2015

Joseph Clark  
Registration number: 120233885  
School of Health and Related Research  
Programme: Health and Related Research (PhD/Health & Related Res FT) - HARR31

Dear Joseph

**PROJECT TITLE:** A Global Social Policy Analysis of Global Palliative Care  
**APPLICATION:** Reference Number 003144

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 27/04/2015 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 003144 (dated 27/04/2015).
- Participant information sheet 1006825 version 1 (26/03/2015).
- Participant consent form 1006848 version 2 (17/04/2015).

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely

Jennifer Burr  
Ethics Administrator  
School of Health and Related Research

## Appendix 2.

### Full list of studies included in Systematic Mapping Review (n=184)

- Abarshi E, Echteld MA, Van den Block L, et al. Use of palliative care services and general practitioner visits at the end of life in The Netherlands and Belgium. *J Pain Symptom Manage.* 2011;41(2):436-48.
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### Appendix 3. Typology of country groups

Country group	Recorded category	Characteristics of group
Group 1	1	<b>No known hospice-palliative care activity:</b> Although we have not been able to identify any palliative care activity in this group of countries, we acknowledge there may be instances where, despite our best efforts, current work has been unrecognised.
Group 2	2	<b>Capacity building activity:</b> In this group of countries, there is evidence of wide-ranging initiatives designed to create the organisational, workforce and policy capacity for hospice-palliative care services to develop, though no service has yet been established. The developmental activities include: <ul style="list-style-type: none"> <li>• attendance at, or organisation of, key conferences</li> <li>• personnel undertaking external training in palliative care</li> <li>• lobbying of policy-makers and ministries of health</li> <li>• incipient service development.</li> </ul>
Group 3a	3	<b>Isolated palliative care provision:</b> This group of countries is characterised by: <ul style="list-style-type: none"> <li>• the development of palliative care activism that is patchy in scope and not well-supported</li> <li>• sourcing of funding that is often heavily donor-dependent</li> <li>• limited availability of morphine</li> <li>• a small number of hospice-palliative care services that are often homebased in nature and relative to the size of the population.</li> </ul>
Group 3b	4	<b>Generalised palliative care provision:</b> This group of countries is characterised by: <ul style="list-style-type: none"> <li>• the development of palliative care activism in a number of locations with the growth of local support in those areas</li> <li>• multiple sources of funding</li> <li>• the availability of morphine</li> <li>• a number of hospice-palliative care services from a community of providers that are independent of the healthcare system</li> <li>• the provision of some training and education initiatives by the hospice organisations.</li> </ul>
Group 4a	5	<b>Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision:</b> This group of countries is characterised by: <ul style="list-style-type: none"> <li>• the development of a critical mass of palliative care activism in a number of locations</li> <li>• a variety of palliative care providers and types of services</li> <li>• awareness of palliative care on the part of health professionals and local communities</li> <li>• the availability of morphine and some other strong pain-relieving drugs</li> <li>• limited impact of palliative care on policy</li> <li>• the provision of a substantial number of training and education initiatives by a range of organisations</li> <li>• interest in the concept of a national palliative care association.</li> </ul>
Group 4b	6	<b>Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision:</b> This group of countries is characterised by: <ul style="list-style-type: none"> <li>• the development of a critical mass of palliative care activism in a wide range of locations</li> <li>• comprehensive provision of all types of palliative care by multiple service providers</li> <li>• broad awareness of palliative care on the part of health professionals, local communities and society in general</li> <li>• unrestricted availability of morphine and all other strong pain-relieving drugs</li> <li>• substantial impact of palliative care on policy, in particular on public health policy</li> <li>• the development of recognised education centres</li> <li>• academic links forged with universities</li> <li>• the existence of a national palliative care association.</li> </ul>

## Appendix 4. Theoretical rationale for inclusion of variables (n=28)

	Indicator	Domain	Description	Year of data	Measure	Total records	Theoretical relationship with palliative care development
1	Cause of death, by non-communicable diseases (NCDs) (% of total)	Disease demographics	Percentage of national population who die due to non-communicable illness. <sup>1</sup>	2000	Scale	171 records	There has been a historical association between palliative care and cancer (a non-communicable disease). <sup>2</sup> Although palliative care is now recommended for both non-communicable and communicable diseases, inclusion of this variable allows an investigation regarding whether palliative care has developed primarily to meet the needs of NCD patients.
2	Cause of death, by communicable diseases (% of total)	Disease demographics	Percentage of deaths resulting from; Communicable diseases and maternal, prenatal and nutrition conditions. <sup>3</sup>	2000	Scale	172 records	The WHO recommends palliative care for any life-limiting illness. However, as palliative care emerged originally to meet the needs of cancer patients, the inclusion of this indicator allows assessment of whether palliative care services have now developed in countries where people predominantly die for infectious illnesses.
3	Life expectancy at birth, total (years)	Socioeconomic	Expected Life Expectancy for a newborn based upon assumed continuation of current mortality rates. <sup>4</sup>	2011, 2010	Scale	195 records	Life Expectancy is considered a key indicator of development as well as a major inequality between nations. <sup>5</sup> Disaggregating life expectancy from the other components of human development score is appropriate in context of the global challenge of ageing populations. Inclusion of this variable allows examination of WPCA claims that palliative care has developed 'to meet the needs of ageing populations'.

<sup>1</sup> World Bank. Cause of death, by non-communicable diseases (% of total). Available from: <http://data.worldbank.org/indicator/SH.DTH.NCOM.ZS>. Accessed 28 December, 2015.

<sup>2</sup> Ten Have J and Janssens R (eds). Palliative Care in Europe: Concepts and Policies. 2001. *Amsterdam: IOS Press*.

<sup>3</sup> World Bank. Cause of death, by communicable diseases and maternal, prenatal and nutrition conditions (% of total). 2015. Available from: <http://data.worldbank.org/indicator/SH.DTH.COMM.ZS>. Accessed 06 January 2016.

<sup>4</sup> World Bank. Life expectancy at birth, total (years). 2015. Available from: <http://data.worldbank.org/indicator/SP.DYN.LE00.IN>. Accessed 28 December, 2015.

<sup>5</sup> Edwards RD. CEPR's policy Portal. Rising inequality between countries in adult length of life. 2010. Available from: <http://www.voxeu.org/article/life-expectancy-around-world>. Accessed 07 November, 2015.

4	Age dependency ratio (% of working-age population)	Socioeconomic	Ratio of older dependents, people older than 64 to the working-age population, those ages 15-64 <sup>6</sup>	2011	Scale	190 records	This indicator is central to discourses around ageing and the sustainability of health systems. Its inclusion allows investigation of whether palliative care has developed most highly, in circumstances where fewer people are paying in to health systems.
5	Literacy rate, adult total (% of people ages 15 and above)	Socioeconomic	Percentage of adults (15+) who can read, write and possess basic numeracy. <sup>7</sup>	2011, 2010, 2009, 2008, 2007	Scale	136 records	The 'Keralan example' also utilises social indicators including literacy rates as contextual factors in the development of palliative care services. <sup>xxxi</sup> Such links provide justification for examining of any relationship between literacy rates and level of palliative care development. It may be expected that higher literacy rates are indicative of higher levels of palliative care development.
6	Out-of-pocket health expenditure (% of total expenditure on health)	Socioeconomic	Any direct household outlay spent on restoration or enhancement of health. <sup>8</sup>	2011	Scale	187 records	This variable allows distinction between public and private health systems. Theoretically, lower out of pocket expenditure is indicative of high commitment from governments to health care. <sup>9</sup> Conversely, greater out of pocket expenditure is suggestive of a greater role of the private sector in the provision of health care. Understanding palliative care development from a public health approach, it may be expected that out-of-pocket expenditure would be lower in circumstances which have higher levels of palliative care development.

<sup>6</sup> World Bank. Age dependency ratio, old (% of working-age population). 2015. Available from: <http://data.worldbank.org/indicator/SP.POP.DPND.OL>. Accessed 28 December 2015.

<sup>7</sup> World Bank. Adult literacy rate, population 15+ years, both sexes (%). 2015. Available from: <http://data.worldbank.org/indicator/SE.ADT.LITR.ZS>. Accessed 28 December, 2015.

<sup>8</sup> World Bank. Out-of-pocket health expenditure (% of total expenditure on health). 2015. Available from: <http://data.worldbank.org/indicator/SH.XPD.OOPC.TO.ZS>. Accessed 28 December, 2015.

<sup>9</sup> Farrington-Douglas J, and Coelho MC. Institute for Public Policy Research. Private Spending on Healthcare. 2008. Available from: [http://www.ippr.org/files/images/media/files/publication/2011/05/private\\_spending\\_on\\_healthcare\\_1646.pdf?noredirect=1](http://www.ippr.org/files/images/media/files/publication/2011/05/private_spending_on_healthcare_1646.pdf?noredirect=1). Accessed 07 November, 2015.

7	Death rate, crude (per 1,000 people)	Socioeconomic	Total deaths per year per 1,000 people <sup>10</sup>	2011, 2010, 2007	Scale	199 records	Crude death rates indicate the number of deaths during the year per 1000 population estimated at midyear <sup>11</sup> and serves as an estimate of the prevalence of death within a population. Estimating death rates is important in terms of assessing potential need for palliative care services. Competing hypotheses are firstly, that high death rates indicate greater need for palliative care and that palliative care may have developed to meet this need. Alternatively, it could be suggested that higher death rates are indicative of underdeveloped health systems where palliative services may not yet have emerged to meet palliative care need.
8	Prevalence of undernourishment (% of population)	Socioeconomic	Percentage of population below minimum level of dietary energy consumption <sup>12</sup>	2011	Scale	125 records	Tackling undernourishment can be considered a global health priority in line with MDG 1: to eradicate extreme poverty and hunger. <sup>13</sup> The line of enquiry here, is that countries where undernourishment remains prevalent are less likely to have developed the infrastructure for palliative care.
9	GINI index	Socioeconomic	Extent to which income distribution or consumption expenditure among individuals or households within a nation deviates from a perfectly equal distribution. <sup>14</sup>	2011, 2010, 2009, 2008, 2007	Scale	152 records	The GINI coefficient is a measurement of the level of income inequality and consumption expenditure within a country. A GINI index of 0 indicates perfect equality, whilst an index of 100 suggests perfect inequality. <sup>15</sup> One theoretical hypothesis for including the variable is that it can be suggested that income equality (or inequality) is not something which occurs naturally, but which is guided by policies. <sup>16</sup> One hypothesis is that more equal societies enjoy greater social cohesions, a circumstance which may have facilitated the development of palliative care. <sup>17</sup> An alternative hypothesis was heard anecdotally by the author, that high income inequality in a country can actually facilitate access to palliative care services, as poorer people seek care as they are unable to seek more expensive curative alternatives.

<sup>10</sup> World Bank. Death rate, crude (per 1,000 people). 2015. Available from: <http://data.worldbank.org/indicator/SP.DYN.CDRT.IN>. Accessed 28 December, 2015

<sup>11</sup> World Bank. Death rate, crude (per 1,000 people). 2014. Available from: <http://data.worldbank.org/indicator/SP.DYN.CDRT.IN>. Accessed 10 December 2014.

<sup>12</sup> World Bank. Prevalence of undernourishment (% of population). 2015. Available from: <http://data.worldbank.org/indicator/SN.ITK.DEFC.ZS>. Accessed 28 December, 2015.

<sup>13</sup> World Health Organization. MDG 1: eradicate extreme poverty and hunger. 2014. Available from: [http://www.who.int/topics/millennium\\_development\\_goals/hunger/en/](http://www.who.int/topics/millennium_development_goals/hunger/en/). Accessed 10 December 2014.

<sup>14</sup> World Bank. GINI index (World Bank estimate). 2015. Available from: <http://data.worldbank.org/indicator/SI.POV.GINI>. Accessed 28 December, 2015.

<sup>15</sup> World Bank. GINI Index. Available from: <http://data.worldbank.org/indicator/SI.POV.GINI>. Accessed 09 December 2014.

<sup>16</sup> International Monetary Fund. Income Inequality and Fiscal Policy. Available from: <http://www.imf.org/external/pubs/ft/sdn/2012/sdn1208.pdf>. Accessed 08 December 2014.

10	International tourism, number of arrivals	Socioeconomic	Total tourist arrivals (under one year) per year <sup>18</sup>	2010, 2008, 2007	Scale	196 records	High levels of international tourism in a country are associate with both positive and negative health outcomes. <sup>19</sup> A theoretical hypothesis is that where large numbers of tourists encounter <i>avoidable suffering</i> – absence of pain relief, for example – that this leads to a response. The work of Ecosphere, a tourism social enterprise, which is helping to introduce palliative care into an isolated Himalayan region in India (Himachal Pradesh), fits with this theory and provides justification to examine any potential broader trends.
11	Internet users (per 100 people)	Socioeconomic	Individual users of the internet per year (per 100 people) <sup>20</sup>	2011	Scale	202 records	The WPCA reported growing awareness of new possibilities, better access to education and training, improved communication systems, access to information as well as ‘broader support networks’ as factors driving palliative care development. ‘Internet use’ was deemed to be a reasonable indicator of access to such systems and processes and was therefore included as a facilitator of such factors on that basis. It may therefore be expected that higher internet use is associated with higher levels of palliative care development.
12	Consumption of morphine equivalent in mg per capita	Health systems	Total opioids distributed to licensed dispensaries (per capita) <sup>21</sup>	2010	Scale	154 records	Opioid consumption is sometimes referred to as the only indicator collated at global level which is relevant to palliative care provision. Morphine equivalents (ME) serve as a good indication of the availability and provision of pain relief within a country, although it does not reveal anything about equity of access in a country. Competing hypotheses are that firstly, availability of morphine equivalents has driven service development. Alternatively, it could be that advocacy from palliative care activists has led to greater ME availability. However, it would be expected, that the higher the level of consumption, the higher the level of palliative care development.

<sup>17</sup> Green A. Preston J. and Janmaat JG. Education, Equality and Social Cohesion: A comparative analysis. 2008, *Palgrave Macmillan*.

<sup>18</sup> World Bank. International tourism, number of arrivals. 2015. Available from: <http://data.worldbank.org/indicator/ST.INT.ARVL>. Accessed 28 December, 2015.

<sup>19</sup> Bauer I. The Impact of Tourism in Developing Countries on the Health of the Local Host communities: The need for more research. *J of Tour Stud*, 1999;10(1):2-17.

<sup>20</sup> World Bank. Internet users (per 100 people). 2015. Available from: <http://data.worldbank.org/indicator/IT.NET.USER.P2>. Accessed 28 December, 2015.

<sup>21</sup> Pain and Policy Studies Group. Opioid Consumption Data. Available from: [http://www.painpolicy.wisc.edu/opioid-consumption-data#What do these data represent?](http://www.painpolicy.wisc.edu/opioid-consumption-data#What%20do%20these%20data%20represent%3F). Accessed 28 December, 2015.

13	Hospital beds (per 1,000 people)	Health systems	Hospital bed available per 1,000 people (public and private) <sup>22</sup>	2011, 2010, 2009, 2008, 2007	Scale	167 records	This variable is included as an indicator of countries' health infrastructure. The measure includes beds at public, private, general, and specialised hospitals and rehabilitation centres. It can be suggested, that the higher proportion of beds to people, the greater the chance that some of these are utilised for palliative patients.
14	Health system ranking	Health systems	Overall health system performance ranking measured in terms of; improvement in health, health system responsiveness and distribution of service <sup>23</sup>	2000	Ordinal	187 records	It has suggested that palliative care is an important element of health systems strengthening. <sup>24</sup> Therefore, it may be suggested that stronger the stronger a health system is, the more likely that palliative care has developed to a high level.
15	Health expenditure, public (% of GDP)	Political	Public health expenditure as a percentage of Gross Domestic Product <sup>25</sup>	2011	Scale	187 records	In general, high public expenditure on health is consistent with social democratic health systems, whereas low spending, is associated with liberal health systems. <sup>26</sup> The hypothesis here is that the greater the proportion of government resources which are directed towards health, the higher the level of palliative care development.

<sup>22</sup> World Bank. Hospital beds (per 1,000 people). 2015. Available from: <http://data.worldbank.org/indicator/SH.MED.BEDS.ZS>. Accessed 28 December, 2015.

<sup>23</sup> World Health Organization. Measuring Overall Health System Performance for 191 countries. 2012. Available from: <http://www.who.int/healthinfo/paper30.pdf>. Accessed 28 December, 2015.

<sup>24</sup> Leng MEF. Health systems strengthening; a palliative care perspective. 2015. Available from: <http://www.cairdeas.org.uk/archive/2015/Health%20systems%20strengthening.pdf>. Accessed 06 January 2016.

<sup>25</sup> World Bank. Health expenditure, public (% of GDP). 2015. Available from: <http://data.worldbank.org/indicator/SH.XPD.PUBL.ZS>. Accessed 28 December, 2015.

<sup>26</sup> Asthana S, and Halliday J. Developing an Evidence Base for Policies and Interventions to Address Health Inequalities: The Analysis of "Public Health Regimes". *Millbank Q*, 2006;84(3):577-603.

16	Health expenditure, private (% of GDP)	Political	Private health expenditure includes direct household) spending, private insurance, charitable donations, and payments by private corporations as a percentage of Gross Domestic Product <sup>27</sup>	2011	Scale	187 records	This variable serves as an indication of political ideology, with higher private spending on health associated with liberal health systems and lower spending, when compared to social democratic models. From a public health perspective, it may be expected that lower private health expenditure would be associated with higher palliative care development.
17	Corruption index	Political	Level of misappropriation of health funding for personal gain <sup>28</sup>	2011	Ordinal	180 records	Globally speaking, health targets have focussed upon the reduction of infectious disease. <sup>29</sup> With increased funding, there is increased political pressure for these targets to be met. High levels of corruption have seen the misdirection of finances made available for health care. <sup>30</sup> Therefore resources which have may been allocated to palliative care development were not spent on developing palliative services. As there are no global targets relating to palliative care, there is little accountability either.
18	Public spending on education, total (% of GDP)	Political	Government spending on education as a percentage of Gross Domestic Product <sup>31</sup>	2011, 2010,2009, 2008,2007	Scale	151 records	This indicator has been included for analysis as a further measure of government commitment to social outcomes amongst its population. Further, the context of Kerala, where educational indicators are highxxx, provides more anecdotal evidence of a potential relationship between these two variables.

<sup>27</sup> World Bank. Health expenditure, private (% of GDP). 2015. Available from: <http://data.worldbank.org/indicator/SH.XPD.PRIV.ZS>. Accessed 28 December, 2015.

<sup>28</sup> Transparency International. Global Corruption Report 2006: Corruption and Health. Available from: [http://www.transparency.org/whatwedo/publication/global\\_corruption\\_report\\_2006\\_corruption\\_and\\_health](http://www.transparency.org/whatwedo/publication/global_corruption_report_2006_corruption_and_health). Accessed 16 December 2014.

<sup>29</sup> United Nations. News on the Millennium Development Goals. 2015. Available from: <http://www.un.org/millenniumgoals>. Accessed 07 November, 2015.

<sup>30</sup> Mackey T. Corruption in Global Health: Governance Approaches in Dealing with Forms of Health Related Corruption. 2011. Available from: <http://www.u4.no/assets/themes/health/Corruption-in-Global-Health.pdf>. Accessed 07 November, 2015.

<sup>31</sup> World Bank. Government expenditure on education as % of GDP (%). 2015. Available from: <http://data.worldbank.org/indicator/SE.XPD.TOTL.GD.ZS>. Accessed 28 December, 2015.

19	Strength of democracy	Political	Composite measure of democracy strength including; pluralism, civil liberties and political culture <sup>32</sup>	2011	Ordinal	167 records	Inclusion of this variable follows other studies which have found a positive effect of democracy upon health. <sup>33</sup> In this regard, it may be expected that palliative care has developed to higher levels within stronger democracies.
20	Population ages 65 and above (% of total)	Demographic	Percentage of total population aged 65+ <sup>34</sup>	2011	Scale	190 records	'The practical needs of an ageing population' has been reported as a driver of palliative care development. The needs of people who die before the age of 65 notwithstanding, including this variable allows us to test the hypothesis that palliative care services have developed to meet the needs of older people (>65).
21	Mortality rate, infant (per 1,000 live births)	Demographic	Total deaths of infants under one year of age (per 1,000 live births) <sup>35</sup>	2011	Scale	190 records	Infant mortality rates are considered a key indicator of health system strength (or weakness). <sup>36</sup> With a health systems approach proposed for palliative care development, it might be expected that high infant mortality rates are an indicator of health system weakness. Global prioritisation of improving infant mortality rates may suggest that this is being prioritised over and above rollout of palliative care.
22	Urban population (% of total)	Demographic	People living in urban areas as percentage of total population <sup>37</sup>	2011	Scale	207 records	The geography and demographics of a country can present unique challenges for health systems to deliver quality health care. In terms of the urban:rural distribution of a population, a major issue centres around access to health services. Additionally, a systematic review reports that palliative care services have developed mainly in urban areas. <sup>38</sup> Inclusion of this variable makes it possible to test this claim.

<sup>32</sup> Economist Intelligence Unit. Democracy Index 2011. Available from:

[http://www.eiu.com/Handlers/WhitepaperHandler.aspx?fi=Democracy\\_Index\\_2011\\_Updated.pdf&mode=wp&campaignid=DemocracyIndex2011](http://www.eiu.com/Handlers/WhitepaperHandler.aspx?fi=Democracy_Index_2011_Updated.pdf&mode=wp&campaignid=DemocracyIndex2011). Accessed 12 December, 2014.

<sup>33</sup> Safael J. Is democracy good for health? *Int J Health Serv*, 2006;36(4):767-86.

<sup>34</sup> World Bank. Population ages 65 and above (% of total). 2015. Available from: <http://data.worldbank.org/indicator/SP.POP.65UP.TO.ZS>. Accessed 28 December, 2015.

<sup>35</sup> World Bank. Mortality rate, infant (per 1,000 live births). 2015. Available from: <http://data.worldbank.org/indicator/SP.DYN.IMRT.IN>. Accessed 28 December, 2015.

<sup>36</sup> Muldoon KA, Galway LP, Nakajima M, Kanters S, Hogg RS, Bendvald E, and Mills E. Health system determinants of infant, child and maternal mortality: A cross-sectional study of UN member countries. *Global Health*, 2011;7(42)

<sup>37</sup> World Bank. Urban population (% of total). 2015. Available from: <http://data.worldbank.org/indicator/SP.URB.TOTL.IN.ZS>. Accessed 28 December, 2015.

<sup>38</sup> Evans R, Stone D, and Elywyn G. Organizing palliative care for rural populations: a systematic review of the evidence. *Family Practice* 2003;20(3):304-310.

23	Birth rate, crude (per 1,000 people)	Demographic	Live births each year per 1,000 persons <sup>39</sup>	2011, 2010, 2007	Scale	201 records	Birth rates have become used as a quasi-indicator of a countries' level of development, with low birth rates prevalent in the countries of high development and higher rates found in lesser developed countries – in particular the world's <i>poorest</i> countries. <sup>40</sup> The theoretical argument for the inclusion of the variable is that in developmental health systems where countries have not yet tackled issues relating to high infant and maternal mortality, they have not been able to focus upon the needs of people at the end of life.
24	Mortality rate, adult, male (per 1,000 male adults)	Demographic	Total adult (15-60) male deaths per 1,000 adult males <sup>41</sup>	2011, 2010, 2009, 2008	Scale	190 records	Mortality rates are included as a useful suggestion of the extent to which palliative care services have developed in response to need. In general terms, proponents suggest that <i>most</i> people would benefit from palliative treatment during the final phase of life – whenever that may be.xxiii On this basis, it can be suggested that higher mortality rates are indicative of greater level of need within a population and the responsiveness of health systems to palliative care need. Distinction between male and female mortality rates have been drawn to take into consideration potential gender difference.
25	Mortality rate, adult, female (per 1,000 female adults)	Demographic	Total adult (15-60) female deaths per 1,000 adult females <sup>42</sup>	2,011,201,0 20,092,000	Scale	190 records	As above

<sup>39</sup> World Bank. Birth rate, crude (per 1,000 people). Available from: <http://data.worldbank.org/indicator/SP.DYN.CBRT.IN>. Accessed 28 December, 2015.

<sup>40</sup> Jackson A. Geography AS Notes. Fertility Rates. 2014. Available from: <https://geographyas.info/population/fertility-rates/>. Accessed 08 December 2014.

<sup>41</sup> World Bank. Mortality rate, adult, male (per 1,000 male adults). 2015. Available from: <http://data.worldbank.org/indicator/SP.DYN.AMRT.MA>. Accessed 28 December, 2015.

<sup>42</sup> World Bank. Mortality rate, adult, female (per 1,000 female adults). Available from: <http://data.worldbank.org/indicator/SP.DYN.AMRT.FE>. Accessed 28 December, 2015.

26	Population growth (annual %)	Demographic	Annual population increase as a percentage of total population <sup>43</sup>	2011 and 2010	Scale	207 records	Generally speaking, growing national populations are associated with low and middle income countries and reducing populations, with high-income – and ageing - nations. <sup>44</sup> The variable has been included as it can be said that there is an increased challenge of rolling out palliative care services to an increasing population. Changing population demographics (growing and reducing) present different challenges to policymakers. However, as palliative care is one recommendation from the United Nations as a policy response to global ageing, it can be said that we may expect to find greater palliative care development in countries where the population is reducing.
27	GNI per capita (constant 2005 US\$)	Economic	National income divided by mid-year population <sup>45</sup>	2011, 2010, 2009, 2008, 2007	Scale	141 records	Gross National Income (GNI) per capita is one element of the composite measure of a country's Human Development score. This variable has been included as it may be suggested, that the higher a nations income, the greater the financial resources which are available to have funded palliative care development.
28	Net ODA received per capita (current US\$)	Economic	Net overseas development assistance divided by midyear population <sup>46</sup>	2011 and 2010	Scale	141 records	Official Development Assistance (ODA) is the term coined by the Organization for Economic Co-Operation and Development (OECD) for the transfer of resources from official agencies and governments which “is administered with the promotion of economic development and welfare of developing countries”. <sup>47</sup> Much ODA is channelled to improving healthcare services of recipient countries. This variable is of interest, as it may be expected that countries are able to provide ODA have higher levels of palliative care development, yet, through ODA , opportunities may have arisen for lower income nations fund palliative care.

<sup>43</sup> World Bank. Population growth (annual %). Available from: <http://data.worldbank.org/indicator/SP.POP.GROW>. Accessed 28 December, 2015.

<sup>44</sup> Haub C. Fact Sheet: World Population Trends 2012. 2012. Available from: <http://www.prb.org/Publications/Datasheets/2012/world-population-data-sheet/fact-sheet-world-population.aspx>. Accessed 07 November, 2015.

<sup>45</sup> World Bank. GNI per capita (constant 2005 US\$). Available from: <http://data.worldbank.org/indicator/NY.GNP.PCAP.KD>. Accessed 28 December, 2015.

<sup>46</sup> World Bank. Net ODA received per capita (current US\$). Available from: <http://data.worldbank.org/indicator/DT.ODA.ODAT.PC.ZS>. Accessed 28 December, 2015.

<sup>47</sup> OECD. Introduction to Official Development Assistance (ODA). Available from: <http://www.oecd.org/dac/stats/intro-to-oda.htm>. Accessed 09 December 2014.

## Appendix 5.

### United Nations Countries and Territories with Palliative Care Rating Excluded from Analysis due to lack of World Bank Comparator (n=27)

	UN countries with palliative care rating excluded due to lack of comparative country classification	PC rating
1	Aland Islands	2
2	Anguilla	1
3	British Virgin Islands	2
4	Cook Islands	1
5	Falkland Islands	1
6	French Guiana	1
7	Gibraltar	3
8	Guadeloupe	3
9	Guernsey	3
10	Holy See (Vatican)	2
11	Jersey	3
12	Martinique	1
13	Mayotte	1
14	Montserrat	1
15	Nauru	1
16	Netherlands Antilles	1
17	NIUE	3
18	Norfolk Island	1
19	Palestinian Authority	2
20	Pitcairn	1
21	Reunion	3
22	Saint Helena	1
23	Saint Pierre and Miquelon	1
24	Svalbard	1
25	Tokelau	1
26	Wallis and Fortuna	1
27	Western Sahara	1

## **Appendix 6.**

### **All countries included within analysis (n=207) by Country group ranking**

#### **Group 1 Countries**

(1) Afghanistan, (4) American Samoa, (5) Andorra, (7) Antigua, (10) Aruba, (21) Benin, (23) Bhutan, (30) Burkina Faso, (31) Burundi, (32) Cabo Verde, (37) Central African Republic, (38) Chad, (42) Comoros, (52) Djibouti, (58) Equatorial Guinea, (59) Eritrea, (62) Faeroe Islands, (66) French Polynesia, (67) Gabon, (73) Greenland, (74) Grenada, (75) Guam, (77) Guinea, (78) Guinea-Bissau, (98) Kiribati, (99) Korea, Democratic Republic of, (103) Lao PDR, (107) Liberia, (108) Libya, (109) Liechtenstein, (117) Maldives, (120) Marshall Islands, (121) Mauritania, (124) Micronesia, (126) Monaco, (135) New Caledonia, (138) Niger, (140) Northern Mariana Islands, (144) Palau, (157) Samoa, (158) San Marino, (159) Sao Tome, (161) Senegal, (168) Solomon Islands, (169) Somalia, (173) St. Kitts, (175) St. Vincent, (181) Syria, (185) Timor-Leste, (186) Togo, (187) Tonga, (191) Turkmenistan, (192) Turks and Caicos Islands, (193) Tuvalu, (200) Uzbekistan, (201) Vanuatu, (204) Virgin Islands, (205) Yemen

#### **Group 2 Countries**

(3) Algeria, (13) Azerbaijan, (14) Bahamas, (24) Bolivia, (43) Congo, Democratic Republic, (54) Dominica, (63) Fiji, (80) Haiti, (81) Honduras, (114) Madagascar, (122) Mauritius, (128) Montenegro, (137) Nicaragua, (142) Oman, (146) Papua New Guinea, (153) Qatar, (163) Seychelles, (177) Suriname, (182) Tajikistan

#### **Group 3 Countries**

(6) Angola, (9) Armenia, (15) Bahrain, (16) Bangladesh, (17) Barbados, (20) Belize, (22) Bermuda, (26) Botswana, (27) Brazil, (28) Brunei, (29) Bulgaria, (33) Cambodia, (34) Cameroon, (36) Cayman Islands, (41) Colombia, (44) Congo, (48) Cuba, (53) Dominican Republic, (55) Ecuador, (56) Egypt, (57) El Salvador, (60) Estonia, (61) Ethiopia, (68) Gambia, (71) Ghana, (72) Greece, (76) Guatemala, (79) Guyana, (86) Indonesia, (87) Iran, (88) Iraq, (90) Isle of man, (93) Jamaica, (96) Kazakhstan, (100) Korea R, (101) Kuwait, (102) Kyrgyz Republic, (104) Latvia, (105) Lebanon, (106) Lesotho, (113) Macedonia, (118) Mali, (123) Mexico, (125) Moldova, (129) Morocco, (130) Mozambique, (131) Myanmar, (132) Namibia, (139) Nigeria, (143) Pakistan, (145) Panama, (147) Paraguay, (148) Peru, (149) Philippines, (155) Russia, (156) Rwanda, (160) Saudi Arabia, (164) Sierra Leone, (172) Sri Lanka, (174) St. Lucia, (176) Sudan, (184) Thailand, (188) Trinidad and Tobago, (189) Tunisia, (195) Ukraine, (196) United Arab Emirates, (202) Venezuela, (203) Vietnam

#### **Group 4 Countries**

(2) Albania, (8) Argentina, (18) Belarus, (25) Bosnia and Herzegovina, (46) Cote d'Ivoire, (47) Croatia, (49) Cyprus, (50) Czech Republic, (69) Georgia, (85) India, (95) Jordan, (110) Lithuania, (119) Malta, (133) Nepal, (151) Portugal, (178) Swaziland, (190) Turkey

#### **Group 5 Countries**

(39) Chile, (40) China, (45) Costa Rica, (51) Denmark, (64) Finland, (83) Hungary, (91) Israel, (97) Kenya, (111) Luxembourg, (112) Macao SA, (115) Malawi, (116) Malaysia, (127) Mongolia, (134) Netherlands, (136) New Zealand, (152) Puerto Rico, (162) Serbia, (166) Slovak Republic, (167)

Slovenia, (170) South Africa, (171) Spain, (183) Tanzania, (199) Uruguay, (206) Zambia, (207) Zimbabwe

**Group 6 Countries**

(11) Australia, (12) Austria, (19) Belgium, (35) Canada, (65) France, (70) Germany, (82) Hong Kong, (84) Iceland, (89) Ireland, (92) Italy, (94) Japan, (141) Norway, (150) Poland, (154) Romania, (165) Singapore, (179) Sweden, (180) Switzerland, (194) Uganda, (197) United Kingdom, (198) United States

## **Appendix 7. Participant Information Sheet. v2.15.04.2015**

### **Participant Information Sheet**

#### **What are the key aspects of a successful advocacy strategy for palliative care at global level?**

You are being invited to take part in a research project. Before you decide whether you would like to take part, it is important to understand why we are doing this research and what your involvement will consist of. Please read the following information and take as much time as you need to consider whether you would like to take part in the study. Thank you for taking the time to read this.

#### **What is the project's purpose?**

Although palliative care is receiving increased attention at global level, worldwide the need for palliative care continues to outstrip supply and palliative care is not considered a global health priority. Global level actors have the power and influence to further the development of palliative care by influencing national-level policymakers as well as by providing the resources to implement projects. Different arguments can be made for palliative care, including; as a humanitarian issue, a human rights challenge and as a way to reduce health system costs whilst providing appropriate care to patients and families. Further, each of these arguments may resonate differently with different global actors. Amidst many competing claims at global level for policy attention and resources, this study explores how advocacy efforts for palliative care can be appropriately focussed at different global actors with a view to furthering the development of palliative care policies and practices.

#### **Why have I been chosen?**

You have been asked to participate as you have been identified as being involved with professional activities relating to international palliative care policy and advocacy. We are seeking to recruit 10-15 participants and you may be asked if you are willing to suggest the names of other people who you feel may be able to contribute to the study.

#### **Do I have to take part?**

No. There is no obligation for you to take part in the study, participation is purely voluntary. You have been given this information to ensure that you understand the purpose of the project and why you are being asked to participate. You will retain the right to withdraw from the study at any time without giving a reason.

#### **What will happen to me if I take part?**

You are being asked to consent to a one-off interview, in which you will be asked a short series of closed and open ended questions. The questions will ask you to reflect upon how palliative care is represented at global level through advocacy. Additionally, you will be asked for your views on how advocacy can become more refined and better focussed. Interviews are expected to last approximately 30 minutes and will be conducted either via telephone, SKYPE or face-to-face at a time of your convenience. If you consent to take part, the interview will be audio-recorded, transcribed and anonymised. All information will be stored securely and your participation would be entirely anonymous. Only the study team would have access to your responses and personal details.

**What are the possible disadvantages and risks of taking part?**

During the interview you will be asked about your professional views regarding palliative and end of life care which some people may consider to be sensitive. As you have been identified as a professional in this field, the risks involved in taking part are considered low. However, if at any stage in the interview questions raise issues which are personally sensitive to you, you may request to pause the interview or withdraw from the study entirely. You will be offered the opportunity to review the transcript from your interview to confirm that it fairly represents your views, but you do not have to do so.

**What are the possible benefits of taking part?**

Although there are no immediate benefits for people taking part in the study, it is hoped that this work will contribute to a greater understanding of how advocacy can be more appropriately targeted at global level actors who have the power and resources to promote the further worldwide development of palliative care.

**What will happen with the results of the project?**

The results of the study will be submitted to the School of Health and Related Research (SchARR) of the University of Sheffield (UK) to be examined for a Doctor of Philosophy degree. The results will also be disseminated through publication in academic journals and conference presentations.

**Who is organising and funding the research?**

The project is funded by SCHARR of the University of Sheffield.

**Does the study have ethical approval?**

Yes. The study has been reviewed by the School of Health and Related Research Ethics Committee who have provided approval for the project.

**What if something goes wrong?**

If you have a complaint about the research project or conduct of the researcher, you should contact:

Jon Nicholl  
Dean of the School of Health and Related Research  
School of Health and Related Research (SchARR)  
Faculty of Medicine, Dentistry and Health  
University of Sheffield  
Regent Court, 30 Regent Street  
Sheffield  
S1 4DA  
Tel: (+44) (0)114 222 5453  
E-mail: [J.Nicholl@sheffield.ac.uk](mailto:J.Nicholl@sheffield.ac.uk)

**Who to contact for further information**

If you have any other questions, please contact the researcher:  
Joseph Clark, School of Health and Related Research (SchARR), The University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA, Email – [joseph.clark@sheffield.ac.uk](mailto:joseph.clark@sheffield.ac.uk)

## Appendix 8.

### Consent Form V2.17.04.2015

#### Participant Consent Form

**Project Title: What are the key aspects of a successful advocacy strategy for palliative care at global level?**

Name of Researcher: Joseph Clark

**Participant Identification Number for this project:**

**Please initial box**

- |   |                          |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated 15.04.2015 explaining the above research project and I have had the opportunity to ask questions about the project.  | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. | <input type="checkbox"/> |
| 3. I give permission for members of the research team to have access to my responses.   | <input type="checkbox"/> |
| 4. I agree for the data collected from me to be used in future research   | <input type="checkbox"/> |
| 5. I understand that my participation will be anonymous.  | <input type="checkbox"/> |
| 6. I agree to take part in the above research project.  | <input type="checkbox"/> |

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Lead Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*To be signed, dated and a copy provided to the participant*

*Once this has been signed by all parties the participant will receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form will also be placed in the project's main site file, which will be kept in a secure location.*