whpca
worldwide hospice palliative care alliance

Universal Health Coverage and Palliative Care



Do not leave those suffering behind





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"I regard universal health coverage as the single most powerful concept that public health has to offer. It is inclusive. It unifies services and delivers them in a comprehensive and integrated way, based on primary health care."

Margaret Chan – WHO Executive Director

1. Introduction

This report has been produced by the Worldwide Hospice Palliative Care Alliance for global and national policy makers and palliative care and global health advocates to highlight the current situation in relation to palliative care and Universal Health Coverage (UHC) and make recommendations for working towards the greater inclusion of palliative care within UHC.

Palliative care is an essential and needed health care service within Universal Health Coverage as defined by the World Health Organization. As the Sustainable Development Goal discussions continue, it is critical that Universal Health Coverage is a key component of that framework but also that no-one is left behind. That includes the millions of people who are living and dying around the world without access to hospice and palliative care, including pain treatment.



2. What is Universal Health Coverage?

Universal coverage, or universal health coverage, is defined as ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.[1]

Universal Health Coverage covers two key elements. The first is that everyone should be able to access a full range of health services including promotion, prevention, treatment, rehabilitation and palliation, within a basic, needed and essential health care package.

The second element is that people are protected from financial risk when they are seeking care. They should not face impoverishment and financial hardship by accessing the health care services that they need.

Central to Universal health coverage is a focus on equity, in that all populations, particularly the poorest and most marginalised, should be able to access the health care services that they require.

There is a growing amount of evidence that a country's progress towards universal health coverage leads to better health, especially for poor people.[2]

3. What is palliative care?

Palliative care aims to improve the quality of life of adults and children living with and dying from life-limiting conditions. The hospice and palliative care approach focuses on meeting the needs of the whole person not just treating their medical condition. It addresses the physical, social, psychological, spiritual issues and other problems faced by those affected and their families.[3]

People need to be able to access hospice and palliative care as soon as they are diagnosed with a life-limiting condition, and not just at the end of life. Ensuring that people are living with life-limiting conditions in comfort and without distress is as important as ensuring a good death. Palliative care is applicable to many life-limiting conditions including non-communicable diseases such as cancer and heart disease and communicable conditions such as HIV and multi-drug resistant TB. For children, the major disease categories which require palliative care are cancer, HIV and progressive non-malignant conditions.[4] For children, there are also congenitally acquired incurable, and perinatal, conditions.

Hospice and palliative care is provided wherever the person is, whether that is in the home, hospital, community clinic or hospice. It is generally provided by a team, depending on the setting and the resources available. This team may include family members, community carers, doctors, nurses, psychologists, pastoral care workers, social workers and others.

Pain management is a key part of hospice and palliative care as it is one of the most common and distressing symptoms that people with serious illness and at the end of life face. To treat a patient's pain, the simplest, least expensive and most effective method is the use of oral morphine. Unfortunately, it is rarely available in many countries. This is due to fears and myths of addiction, over regulation and lack of training in pain management and understanding of the use of opioid medication



Madam Ah Chee, patient of Hospis Malaysia

Supporting family members and carers, including in the bereavement period, is a key aspect of palliative care. This is to improve their own quality of life and well-being and to help ensure the best quality of care for those that they are caring for.

4. Palliative care as an essential, needed health service within Universal Health Coverage

It is a needed and essential health service

Palliative care is a needed and essential health service within the definition of Universal Health Coverage. It is estimated that over 40 million people require palliative care each year throughout the trajectory of a given medical condition. Of the 20 million that require palliative care at the end of life, it estimated that 18 million people do not receive it. 78% of those who require hospice and palliative care at the end of life are based in developing countries.[5]

Universal Health Coverage aims to ensure that countries develop a universally accessible health system for all citizens that meets population health needs and priorities. Palliative care is a population health need and a priority particularly given the aging population and growing incidence of non-communicable diseases including dementia. It must be part of an integrated approach and a fundamental component of the continuum of care throughout the life course.

The need for access to palliative care services as a key part of Universal Health Coverage has been reiterated since palliative care was included in the definition in 2012.[6] In May 2014, the palliative care resolution was adopted at the World Health Assembly which calls on governments to "integrate palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-base care, and universal coverage schemes."[7]

It can improve quality of life and prevent suffering

Palliative care can improve quality of life for people with many life-limiting conditions including HIV, cancer and MDR TB.[8] Improving quality of life has often been neglected in public health discourse with a focus on prevention and cure and lives saved. It can be argued that this has been at the cost of alleviating suffering. However, Universal Health Coverage is about the full spectrum of basic and needed health care services from pre-natal to birth to death, and includes health promotion. Palliative care is a fundamental part of the health care response and it is government's role to ensure a health care system that treats the needless suffering of its population right up to the end of life.

It is a human right

Palliative care, including access to pain treatment, is recognised as a human right. The International Covenant on Economic, Social and Cultural Rights "recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". This includes "the creation of conditions which would assure to all medical service and medical attention in the event of sickness".[9] Access to health services such as hospice and palliative care, including access to opioid medications, must be available to all.

It is the fair, equitable and decent thing to do

Universal Health Coverage requires autonomy by countries to select the interventions that are required for their particular setting within the resources that they have available. While cost-effectiveness is likely to be a key deciding factor, in the World Health Report 2010, it was clearly recognised that "cost-effectiveness is not the only consideration when deciding on an optimal mix of interventions. In cases where fairness, equity or basic decency are at issue, the social value of a particular health intervention may differ from the value of the health benefits it produces." The report went on to use end-of-life care as an example of how in some instances 'social values rather than cost-effectiveness considerations determine that societies will continue to provide end-of-life care."[10]

It can be cost-effective

There is increasing evidence to support the idea that palliative care is a cost-effective intervention. Palliative care can tackle some of the key issues addressed as 'leading sources of inefficiency' in health care in the WHO 'Arguing for Universal Health Coverage' publication,[11] most notably, 'inappropriate hospital admissions and lengths of stay'[12] and the 'inappropriate and ineffective use of medicines'.

5. Barriers to the provision of palliative care within Universal Health Coverage

5.1 Availability and accessibility of services and medications

Universal Health Coverage requires availability and accessibility of services to meet the needs of the whole population. However, palliative care services are far from being integrated into main-stream health services. In fact, it is estimated that only 20 countries globally have palliative care integrated into the mainstream health system.[13] 42% of countries have no known hospice and palliative care services at all.

Figure 1 was published in the Global Atlas on Palliative Care at the End of Life Care and shows provider services to population. The vast majority of countries worldwide have very low number of services per 1,000,000 population with limited coverage. Figure 2 shows the estimated numbers of patients receiving palliative care.

Lack of access to opioid analgesics especially morphine is a particularly challenging issue which poses a barrier to Universal Health Coverage. Figure 3 shows the huge inequities in access to pain medications worldwide. The metrics or data are not currently available to show the extent of equitable utilisation of hospice and palliative care, including access to pain medications, across different wealth strata.

Figure 1

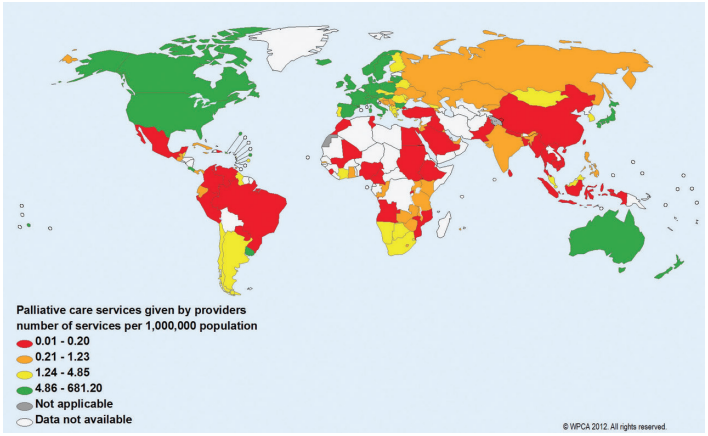


Figure 2

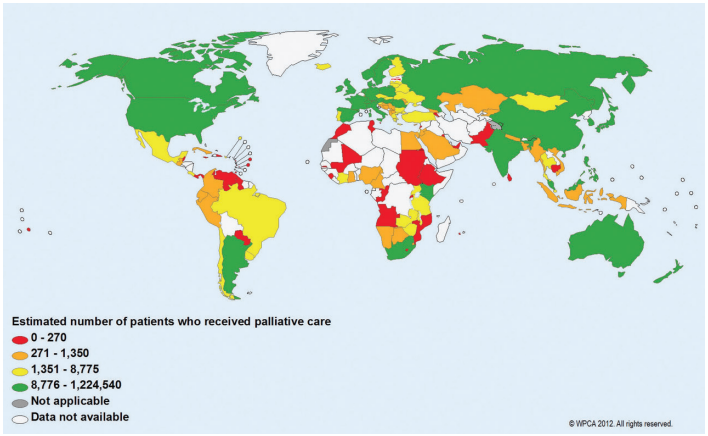
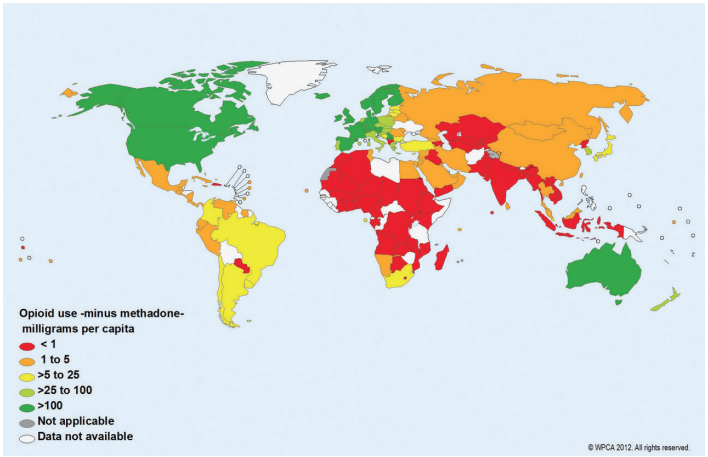


Figure 3



5.2 Human resources for health

Human resources for health are vital to achieve Universal Health Coverage and to provide comprehensive health services to address the range of people's needs including promotion, prevention, treatment, rehabilitation and palliation.[14]

However, there are significant challenges in the numbers and training of health care workers in palliative care. In particular, education and training has been lacking resulting in limited awareness amongst health professionals about palliative care and a lack of inclusion of palliative care in the curricula for health professionals around the world.[15]

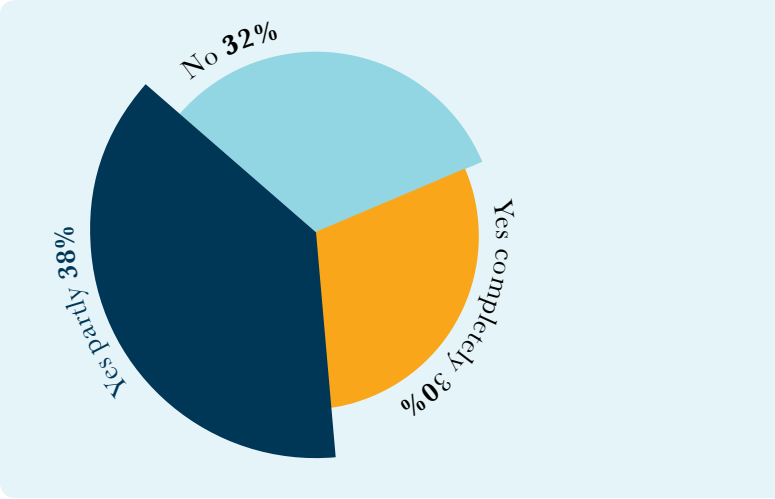
The challenges of human resources for health include inadequate numbers by cadre in the health systems where they are required, inadequate country budgets to hire even where they exist, lack of palliative care expertise and skills where they are employed and poor distribution between rural and urban centres.[16]

For example, in India, a study showed that awareness of undergraduates about palliative care and pain medications was very low[17] and clearly showed the need for the inclusion of palliative care in undergraduate medical, nursing and allied health training. In Serbia, the lack of inclusion of palliative care in medical, nursing and allied curricula was recognised as a major barrier to the development of palliative care and is now included in most curricula.[18]

5.3 Palliative care within health insurance and financial protection schemes

The WHPCA conducted a rapid survey of organisations and individuals engaged in palliative care globally. There were 70 responses from 43 countries. Feedback was collated and analysed to provide one combined response per country. 79% (34) of the country respondents stated that the government had free health care or health insurance schemes. 16% (seven respondents) stated that their government did not have free health care or health insurance schemes. 5% (two respondents) did not know or did not answer.

Figure 4 – Data from respondents on palliative care inclusion from the 34 countries[19] who said that the government did have free health care or insurance schemes



It is important to note that there is likely to be a bias towards those who responded from countries with an understanding and awareness of Universal Health Coverage, and the potential place or existence of palliative care within it. Countries with palliative care organisations and individuals less engaged on UHC appear to have been less likely to respond.

Even where countries have medical insurance schemes for the parts of the population, certain conditions may be excluded. An example is Ghana where the National Health Insurance is currently the only pro-poor health financing intervention. The only cancers covered by the scheme are breast and cervical cancers[20] and the scheme does not clearly cover palliative care.

5.4 Evidence base

There is a strong and increasing evidence base on how palliative care improves patient outcomes and in particular quality of life. However, while there is some evidence on the cost and cost-effectiveness of palliative care, more research needs to be done, especially in low and middle income

countries. In relation to the extent that countries prioritise palliative care, lack of evidence around the cost of palliative care, the differing costs of different service delivery methods and its overall cost-effectiveness may result in challenges to palliative care implementation as part of Universal Health Coverage.

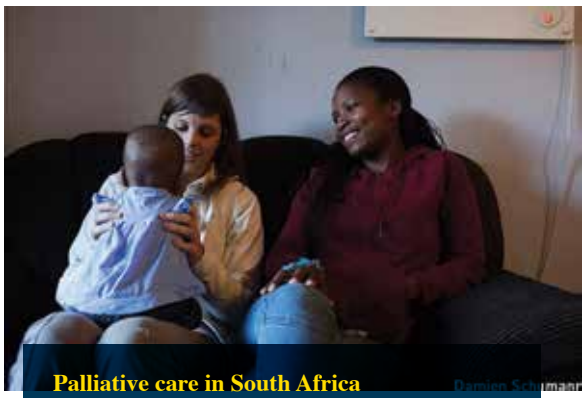
5.5 Palliative care within Universal Health Coverage analysis and commentary

Palliative care is often not included in key discourse, commentary, analysis and research on the issue of Universal Health Coverage. When it is included, it is only often in reference to the UHC definition of basic and essential health services, and not explored further. This absence in the discourse represents in itself a barrier to the development of palliative care.

As an indicative example, the Lancet Global Health Series has made excellent contributions to highlighting the current evidence and commentary on Universal Health Coverage. However, the most recent Lancet Global Health Series of 4 articles on Universal Health Coverage in Latin America did not include a single mention of palliative, hospice care or palliation.[21] In one article of the series palliation was not even included within the descriptive text of 'personal' health services which are defined as 'preventative, diagnostic, therapeutic, and rehabilitative actions'.[22] Palliation is mentioned once in one commentary piece in this particular Lancet edition, but only in reference to the definition of Universal Health Coverage and a need to strive to meet a comprehensive range of services as a moral imperative.[23] It is hoped that this will be tackled by the HGEI-Lancet Commission on Global Access to Pain Control and Palliative Care.







Palliative care in South Africa

5.6 Monitoring

Monitoring of palliative care as part of Universal Health Coverage is challenging. The issues include a lack of agreed, quality, comparable indicators, absence of routine data collection and inclusion within existing data collection tools as well as challenges with disaggregating data to show the equity of access and coverage. This issue is covered more thoroughly on pages 12–14.

6. Palliative care and financial hardship

A core component of Universal Health Coverage is ensuring that people do not face financial hardship by accessing, or a lack of access to, basic and essential health care services. In reality this is exactly what happens to millions around the world in accessing palliative care, and indeed pain treatment.

When families are affected by life-limiting illnesses, they are often severely affected financially as they are either unable to work due to their condition,[24,25] or family members are unable to work due to their caring responsibilities.[26] This can have a devastating impact on household income, making the purchase of basic necessities such as food and clothing a challenge.

In addition, in many parts of the world, hospice and palliative care services, and places to access pain medications, are often sparsely distributed. These services and medications are often only available in certain locations e.g major cities.[27] For this reason, people end up travelling long distances, at significant cost, in order to get the care that they need. Home care is often not available, or not included in health coverage insurance and schemes.

In many parts of the world, civil society and the voluntary sector have developed services which are free at the point of use and funded by the communities. In some settings government have palliative care, partly if not completely, included within their Universal Health Coverage schemes. However, there are often poor protection systems in place to provide financial support for carers and households facing economic crisis due to the loss of household income because of life-threatening illness or caring responsibilities for family, including older parents and children, or community members.



Chek Jamal, patient of Hospis Malaysia

7. The inclusion of palliative care within Universal Health Coverage – national case studies

The financing of hospice and palliative care around the world is complex. Varying models and systems of service delivery are accompanied by various funding modalities, including public, private and community funding. This is also reflected in the extent to which palliative care is included in Universal Health Coverage schemes. The following case studies provide a snap shot of the situation in five countries around the world.

7.1 England – a case study

In England, palliative care, including access to pain treatment, is recognised as a fundamental part of the health care system and is free at the point of use to all UK residents. The National Health Service, and its palliative care services, is paid for through taxation.[28]

However, a significant proportion of palliative care is provided by hospices, the majority of which are non-governmental and only get approximately 34% of government funding. Hospices provide free care for all, paid for by public donations and fundraising. Theoretically, all patients therefore should receive hospice and palliative care without financial hardship.

One of the challenges that has led to long standing debate in the English hospice and palliative care funding discussion has been what elements of hospice and palliative care the government should be paying for, and what is deemed the responsibility of the community. In 2010, the government commissioned a palliative care funding review. The review identified major issues with developing a new funding system including 1) that in excess of 90,000 people in the UK per year have unmet palliative care needs, 2) that there are significant challenges in developing a currency which covers both adults and children's palliative care as this does not exist anywhere else in the world and 3) that there is a lack of quality data surrounding the cost of palliative care at the national level.[29]

Pilot data collection was undertaken in 2011 and the data was utilised to try and develop a palliative care currency, e.g. consistently identified units of care, which can then be used as a basis for costing and payment. Due to the specific approach of palliative care, the government suggestions for a palliative care currency are based on the needs of the patients rather than the procedure performed. The aim of the proposal is to ensure that hospice and palliative care providers are fairly reimbursed by the National Health System for the services they are providing, while the National Health Service is assured that the services are cost-effective. This proposal is currently under consultation.

While palliative care services are accessible and available for people living with life-limiting illness in England, there are still challenges with financial hardship as a result of caring responsibilities. A survey of 4924 carers in the UK found that 54% are struggling to pay household bills and to make ends meet, and over a third of all carers (35%) are cutting back on essentials like food and heating.[30]

7.2 Singapore – a case study

Hospice and palliative care is at a high level of integration within main-stream health systems in Singapore (one of only 20 countries in the world) as outlined in the *Global Atlas on Palliative Care at the End of Life*. Singapore offers universal healthcare coverage to its citizens, with a financing system anchored on the twin philosophies of individual responsibility and affordable healthcare for all. The health system is financed through a mixed system including government subsidies, compulsory individual savings, a catastrophic medical insurance and a medical endowment fund to act as the ultimate safety net. Hospice and palliative care is covered to a greater and lesser extent in these schemes. In addition, there are eight independent hospices largely supported through donations with some government funding and user fees.

Singapore has mandatory savings account scheme, called Medisave. Depending on their age, a working Singaporean contributes between 7–9.5% of his or her monthly salary into this personal account.[31] Medisave can be used for hospice and palliative care inpatient or home services. Home care services are delivered by charitable hospices and subsidised by the state between 50–75%. The rest is covered by charitable donations. The Minister of Health stated in 2009, "I think we welcome their free service for

certain sectors of the population but if we really want to grow this sector, the service cannot be free all round… So I think there is scope for home palliative care… I'm preparing the ground for this growth."

Currently, Medisave can be used for approved hospices, up to $160 per day for the daily hospital charges, including a maximum of $30 for the doctor's daily attendance fees. In June 2014, the Singaporean Ministry of Health announced important changes in the scheme to come into effect in January 2015. For those who require palliative care, the cap on withdrawals will be increased from $160 per day to $200 per day and the lifetime limit for home palliative care from $1500 to $2500 from 1 January 2015. However, for those who have terminal conditions, the cap will be lifted completely with no restriction on what they take from the Medisave account. If people have used up all their medisave resources, they are able to use that of their immediate relatives.

The Medifund scheme was set up as a safety net for those who do not have the resources to pay for their treatment. "Only subsidised patients attending the specialist outpatient clinics in approved hospitals and medical institutions, and who are unable to pay the charges can benefit from Medifund."[32] Medifund covers inpatient and hospital and hospice palliative care. It also cover hospice at home services, but these are provided free of charge to patients through charitable hospice services, therefore its inclusion is essentially redundant. However, should charitable hospices have to consider charging in the future then its inclusion would be critical.

7.3 Mexico – a case study

In 2004, the Government of Mexico introduced Seguro Popular, a national protection programme mainly financed through general taxation and contributions from wealthier households. By 2014, 53 million people had enrolled and the programme saw a significant drop in impoverishment and the incidence of catastrophic expenditure.[33] Mexico also has several other public insurance schemes including social insurance, which covers nearly all of Mexico's population, and insurance for state workers.

However, a recent report by Human Rights Watch[34] identified two challenges with the availability and accessibility of palliative care in Mexico. One challenge is the inclusion of appropriate and needed palliative care entitlements under the insurance packages. The second challenge is the actual availability of hospice and palliative care services through hospitals, clinics and in the home in the networks of insurers.

The report found, for example, that Seguro Popular only covers palliative care partially. Although the National Commission for Social Protection in Health, which runs Seguro Popular, recently added a number of palliative interventions and medications to its package, psychosocial interventions, home-based care and oral morphine are not yet covered. Despite the fact that these interventions have been show to be cost-effective, It noted that Seguro Popular is currently considering expanding coverage of palliative care.

The Mexican Social Security Institute theoretically covers any needed palliative care intervention. Yet, its network of hospitals has palliative care units in just three hospitals around the country. As a result, the report notes that "many patients end up without access to palliative care, even if their insurance entitles them to such care". Furthermore, primary and secondary health facilities within the social security system cannot prescribe opioid analgesics. The institute has announced an intention to strengthen the availability of palliative care.

While significantly more hospitals in Seguro Popular's network have palliative care units, such care remains out of reach for many of its beneficiaries. Seven of Mexico's thirty-two states have no known palliative care services. Another 17 only have them in state capitals, far from where most patients live. Finally, the report notes that opioid analgesics are almost completely unavailable outside of state capitals, and home palliative care services are limited.

7.4 South Africa – a case study

In South Africa, palliative care is classified as being at a preliminary stage of integration with mainstream health systems. South Africa does not currently have a Universal Health Coverage policy. However, the proposed National Health Insurance is currently being piloted in 11 health districts. This pilot does not formally include hospice and palliative care services.

Currently, the majority of hospice and palliative care in South Africa is provided by independent hospices who provide care free to patients at the point of use. These hospice services raise funds independently from communities, corporates and trusts, with less than 10% funding from government. A very small proportion of palliative care is funded by private health insurance. It is estimated that less than 25% of those in need have access to free hospice and palliative care services in South Africa. For children, this is presently less than 5%.[35]

Like in many settings the need to access hospice and palliative care can have a devastating financial impact on households. As people with life-limiting illness and their carers are unable to bring in income due to their condition or caring role, households can be forced further into poverty.

South Africa was one of the countries sponsoring the WHA resolution 67–19 *Strengthening of palliative care as a component of comprehensive care throughout the life course* and the South African government is working with palliative care advocates to integrate palliative care into the health system. It is important that this includes funding for palliative care services.

7.5 Republic of Ireland – a case study on children's palliative care and Universal Health Coverage

The Republic of Ireland has a national health system paid for by the government through taxation. People do however have to pay for GP visits and to attend Accident and Emergency. If you are unemployed, on a low income or are chronically sick, you are entitled to a medical card. There are differing types of medical card with some giving completely free health care including prescriptions and others just entitling you to free GP visits. Many people have private health insurance, often through work-based schemes.

Children's palliative care is partly included in the universal coverage scheme. The development of children's palliative care in Ireland has been largely driven by the voluntary sector. The Irish Hospice Foundation pump-primed the first children's palliative care consultant and the appointment of eight children's palliative care nurses to coordinate care for families of children with life-limiting conditions. These posts were appointed (five years or the consultant and three years for the nurses) with a promise by the Health Service Executive that they would take over the funding of the appointments.

There is one children's hospice in the Republic of Ireland. This provides care for children with life-limiting conditions free at the point of delivery but receives no state funding at all. It is fully funded by voluntary sector fundraising. The health system provides some home palliative care for children but largely as a supplement to the work of voluntary organisations. The same is true of medications and equipment.

In essence, while the system partly supports children's palliative care the provision and equity of access is dependent on the diagnosis, parental knowledge of the system and geographical location of the family home. Some children and their families who are in need are in receipt of comprehensive palliative care services free of charge, others are not. Investment in children's palliative care was recently a recommendation of a government committee looking at end-of-life care in Ireland. An equitable and coordinated approach to care is needed to ensure all children with life-limiting conditions and their families receive the care they need.

8. Global monitoring of palliative care, within Universal Health Coverage

In May 2014, the WHO and the World Bank Group published their framework "Monitoring progress towards Universal Health Coverage at country and global levels: Frameworks, measures and targets". One of the guiding principles of the framework is that "Measures of coverage should comprise the full spectrum of essential health interventions – promotion, prevention, treatment, rehabilitation and palliation – and their associated costs." The framework however then goes on to clarify how it adopts 'tracer' indicators, with palliation and rehabilitation being included within treatment.

Indicators were assessed and selected according to three levels of criteria. These were:

- **Relevance**: Do the indicators measure health conditions that are priorities?
- **Quality**: Do the indicators represent effective or quality adjusted coverage?
- **Availability**: Are the indicators measured regularly, reliably and comparably (e.g. numerators, denominators, equity stratification) with existing instruments (e.g. Household surveys or health facility information systems).

Very few indicators across the spectrum of interventions met all criteria and all the 'treatment' indicators really are treatment indicators rather than rehabilitation or palliation. It implies within the report that existing indicators for palliation are not sufficiently comparable or reliable measures of coverage. This statement is also backed up in the World Health Report 2013 which states that "beyond the MDGs there is less experience in monitoring prevention and control in other areas of health, such as non-communicable diseases, ageing, and rehabilitation and palliative care. Similarly, while there are some standard indicators of the quality of health services, of equity of access, and of financial risk protection, there is much scope for refining the methods of data collections and measurement."[36]

The indicator proposed by the Worldwide Hospice Palliative Care Alliance, and a number of other agencies, as a tracer indicator to monitor palliative care as a component of Universal Health Coverage was 'Access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesics (excluding methadone & pethidine) per capita". However, according to WHO, this indicator did not reach the required standards in relation to the extent to which it measured coverage. While the indicator is evidently relevant, and is measured regularly, reliably and comparably, crucially, there is currently no way of disaggregating data to measure the equitable coverage to ensure that palliative care, or the consumption of opioids for pain treatment, is reaching the poorest in society. The indicator measure is also affected by population demographic variability in age cohorts and disease incidence.

The existence of agreed, routine and comparative use of palliative care indicators at the global and national level is clearly problematic. To date there has only been one indicator agreed by the UN as part of the global monitoring of hospice and palliative care which was the indicator for the Global Action Plan on Non-Communicable Diseases. This is currently the only palliative care indicator in the WHO Indicator and Measurement Registry.[37] It is not mandatory that countries report on this indicator. While great progress has been made in monitoring of palliative care development, this has largely been driven by civil society, particularly by the WHPCA (in collaboration with WH0) with the *Global Atlas on Palliative Care at the End of* Life and the WHO Collaborating Center for Palliative Care Public Health Programs in Barcelona that has developed population estimates on the need for palliative care. In addition, mapping has been done at the regional levels particularly in Europe and Latin America. However, more work needs to be done to get indicators agreed nationally and globally.

A further challenge is the lack of routine and consistent monitoring and data collection of palliative care within existing instruments. A particular example of this is the complete absence of collection of palliative care data within Demographic and Health Surveys (DHS) and Service Provision Assessments (SPA).[38] Without

palliative care data collected in a routine manner at this level, it will continue to be difficult for palliative care indicators to get passed through the rigid assessment criteria.

And yet, despite the challenges the principle remains that measures of UHC should comprise the full spectrum of essential health services including palliation, and currently they do not. To propose the measurement of Universal Health Coverage utilising treatment indicators as tracers for access to palliation is inadequate. These tracer indicators are unlikely to prove a tracer in any way to the availability and accessibility of palliative care services for those who need them, including the poorest, and thereby do not provide an adequate measure of Universal Health Coverage.

While recognising the technical challenges, the WHPCA continues to advocate for the inclusion of 'Morphine equivalent consumption (excluding methadone) per capita' as a tracer indicator for palliative care within the Universal Health Coverage monitoring framework, and as an indicator within the Sustainable Development goals framework. This indicator should be demographically adjusted and utilised while the WHO, governments, technical assistance agencies and civil society work to improve data collection and indicators on palliative care.



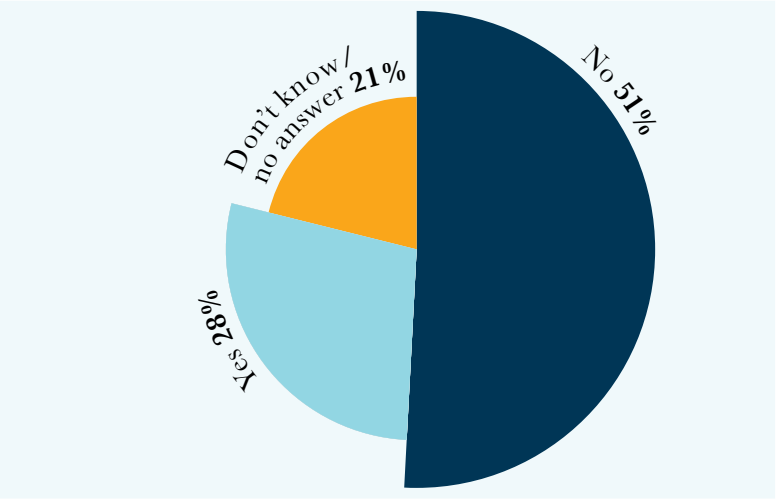
Patient from Hospice Africa Uganda

Credit: Steve Hynd, African Palliative Care Association

9. National monitoring of palliative care, as a part of Universal Health Coverage

In the survey of palliative care and advocacy practitioners, we questioned the extent to which governments measured palliative care coverage and what was the main indicator used. Irrespective of whether or not a country had a Universal Health Coverage policy, or had achieved it, of the 43 country respondents, 22 country respondents said that there was no national measurement of palliative care by governments in their countries. 12 said there was national measurement of palliative care coverage by governments. Nine did not know or did not respond. This indicates that measurement of palliative care nationally is very low.

Figure 5: Data from 43 country respondents on whether governments measured palliative care coverage nationally



For those who responded that there was national measurement of palliative care, when asked to identify the key indicators used to measure coverage, responses were varied and included 'number of patients receiving morphine', 'home deaths', 'number of palliative care admissions to hospitals', 'patient satisfaction' and 'improvement for support for families'.

A more comprehensive study and analysis needs to be done to see what indicators are used and the extent to which they actually measure coverage of palliative care, or disaggregate data, but either way it is possible to suggest from the varied responses that, where measurement exists at all, currently data collection or measurement is neither standardised nor comparable across nations.

As discussed previously the absence of key data collection, including palliative care in household surveys and facility assessments affects the ability to measure progress in relation to universal health coverage. A review of progress in relation to UHC in India showed that the 'paucity of routine and disaggregated data' was problematic and indicators were chosen on the basis of availability of surveys done across various years.[39]

In relation to Universal Health Coverage, countries often rely on international survey programs or national surveys to obtain disaggregated data on coverage and financial protection indicators, complemented by health facility data, but often the frequency and contents of these surveys are not sufficient to meet the country's information needs."[40] It is likely that palliative care is rarely, if ever, including in these surveys.

Countries such as the UK, South Africa and the US have national monitoring of palliative care but the data is not comparable or standardised with other countries.

10. Global Advocacy on palliative care and Universal Health Coverage

Given the challenges outlined in this report in relation to palliative care inclusion within Universal Health Coverage, there is a need for much more advocacy on the issue. At the national level, many respondents to the WHPCA survey had spoken to their governments about palliative care and Universal Health Coverage and knew of NGOs in their country advocating on Universal Health Coverage.

In addition, global advocacy has occurred on palliative care and Universal Health Coverage but more needs to be done. The following outlines a selection of examples of past or ongoing advocacy activities relating to palliative care and UHC.

In 2011, the Worldwide Hospice and Palliative Care Alliance recognised the absence of palliative care within the definition of essential and needed services within UHC. At a global health meeting in London, where David Evans was a speaker, the WHPCA raised the issues with Dr Evans and WHO. As a direct result of these discussions, the WHO agreed to add palliative care to the definition of essential and needed health services. This was utilised in documentation at the World Bank and WHO meeting of technical experts in Geneva, and has been consistently used since.[41]

Since 2012, the central theme of World Hospice and Palliative Care Day has been focussed on "Achieving Universal Health Coverage" with sub themes including addressing the myths of hospice and palliative care and the issues of health care workers in palliative care. The theme in 2015 will be 'hidden lives' looking at those who are often neglected or left behind. Grassroots activities take place in approximately 60 countries worldwide.

In 2013, the WHPCA coordinated and developed a paper on a palliative care indicator which was proposed to WHO to be part of the Universal Health Coverage Monitoring Framework. This indicator was not included although the monitoring framework states "the core set of interventions can be built upon over time as, and when comparable, reliable measures of coverage for other intervention areas, such as rehabilitation and palliation, become available"[42]

At the World Health Assembly in 2013, the International Association of Hospice Palliative Care raised the question of the inclusion of palliative care within Universal Health Coverage schemes at a side event hosted by the ASEAN plus 3 countries on Universal Health Coverage. Senior health officials from Malaysia, Thailand, and Indonesia responded in the affirmative, either they stated that palliative care was fully integrated, or that they are working towards integration.[43]

In 2014, advocacy by a number of palliative care groups and Human Rights Watch led to the adoption of the palliative care resolution at the World Health Assembly which includes a statement on the need for palliative care to be included in Universal Health Coverage schemes.

In 2014, the Worldwide Hospice Palliative Care Alliance published a position statement on "Palliative care: a needed and essential service within Universal Health Coverage".[44] The position statement called on policy makers to ensure that equitable access to, availability and usage of palliative care is included in all plans to progress towards Universal Health Coverage.

In 2014, the HGEI-Lancet Commission on Global Access to Pain Control & Palliative Care had their inaugural meeting in New York. The Commission recognises, and aims to address the issue that "Universal Health Coverage – a now widely accepted goal of health systems – has largely ignored the need for pain control and palliative care" by coupling "evidence based advocacy with advocacy inspired evidence."[45]

In 2014, Human Rights Watch published a report focussed on access to pain treatment and palliative care in Mexico which had strong inclusion of the situation regarding palliative care in the health system in Mexico and how palliative care fits within their progress towards Universal Health Coverage.

In 2014, the Worldwide Hospice Palliative Care Alliance was one of the founding global partners of the first ever Universal Health Coverage Day.[46]

11. Opinions and perspectives from the palliative care world

In the survey of hospice and palliative care advocates and practitioners, we posed the question of the extent to which they thought Universal Health Coverage was important for the development of palliative care, the following were some comments that were made:

"Universal Health Coverage is important if we are to push for hospice and palliative care in our country. It should be included in its framework. Our government I think knows this but does not or cannot or will not do it. I don't know how to move it forward without money or people. We need to reach the people who need it most."

Rhodora Ocampo, Madre de Amor Hospice Foundation, The Philippines

"Universal Health Coverage is very important in my country because many people suffer with lots of life limiting conditions. The cost of health care is really very expensive and many people and families with palliative care needs are only seen by the palliative care department when they have spent all they have subjecting the entire family to misery. If UHC is done, this will impact positively on a huge number of the population."

Ndzi Eric Ngah, Cameroon Baptist Convention Health Services, Cameroon

"Universal Health Coverage is the only way the government of Cyprus will be forced to accept palliative care as an important health discipline not only for cancer patients but all patients, adults and children, living with chronic illness. Unfortunately, it is still unclear whether palliative care will be included in the national health scheme to be implemented in Cyprus in 2015."

Barbara Pitsillides, PASYKAF, Cyprus

"Universal Health coverage is an important issue for hospice and palliative care because there are a lot of patients with life threatening diseases whose poverty situation limits them to access to essential drugs and care and mystery and suffering is really alarming in our poor communities. Patients who can't be sure of a square meal for the day cannot pay for essential drugs, not to talk of palliative care. The situation is really serious and needs some urgent attention."

Wepnje Joseph Mupbah, Cameroon

"Universal Health Coverage is important because it is a means to universalize palliative care services for people, no matter their economic or social status."

Maria Laura Daud, Fleni and Pallium Latinamerica, Argentina

"Universal Health Coverage is important for palliative care because everybody will die and people suffer a lot even if they have a sophisticated but not proportional assistance or if they are abandoned with lots of symptoms without adequate control. So Palliative Care is an essential part of universal health coverage."

Maria Goretti Sales Maciel, Argentina

"Hospice and palliative care is a basic need for any individual because Health Coverage must be provided for all whether their condition is curable or terminal."

Bruce Tam Wai Chung, Grace Health Care Limited, Hong Kong

"Univeral Health Coverage is an important issue for hospice and palliative care in Morocco because 75% of Moroccan have no insurance"

Prof Mati Nejmi, Clinik Al Farabi, Morocco

"Individuals can't improve the present situation. I was trying to start a palliative care ambulance last year and the health insurance company didnt allow it. They accepted one-day surgery places, but not this..."

Otrubova Zuzana, Slovakia



Patient from Mulago Hospital, Kampala

Credit: Steve Hynd, African Palliative Care Association

12. Recommendations

Policy

- Palliative care should be included within Universal Health Coverage global and national policies and strategies, along with allocated budget and appropriate resourcing for implementation to improve access and availability to meet the needs of the population.

Service delivery and implementation

- Hospice and palliative care needs to be fully integrated into main-stream health systems, including linkages with Non-Communicable Diseases and HIV service delivery, to ensure effective coverage to meet the palliative care needs of the population.
- Service delivery and implementation of Universal Health Coverage must ensure that no-one is left behind, including adults and children who are suffering throughout the life course, due to life-limiting conditions.

Education

- Palliative care should be integrated in all pre-service health worker training (e.g. doctors, nurses, clinical officers, social workers etc) and as continuing professional development.

Financing

- A thorough review should be undertaken of the inclusion of palliative care within health financing systems, including relevant health insurance and national health care schemes globally.
- Palliative care interventions, including home based and inpatient hospice and palliative care and access to opioid analgesics, must be accessible to all and therefore included within national health financing systems such as health insurance and universal coverage schemes.
- More rigorous and robust research needs to be done on the cost of hospice and palliative care and its cost-effectiveness.
- More research is required on the financial burden that households face as a result of accessing, or not being able to access, hospice and palliative care services.

Monitoring and evaluation

- An appropriate indicator must be added to the global monitoring framework on Universal Health Coverage to ensure the measurement of palliative care.
- Basic, standardised and routine data collection of palliative care needs to be including in existing tools such as health surveys and facility assessments. Palliative care indicators should be part of each country's Health Management Information Systems (HMIS).
- Research has to be done to source relevant, quality and comparable indicators and data collection tools to improve the ability to monitor the equitable coverage of palliative care for all people, particularly the poorest.

Advocacy

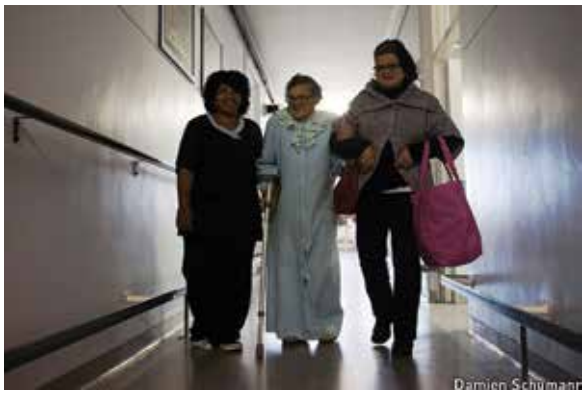
- Palliative care civil society providers and organisations need to advocate for the consistent and rigorous inclusion of palliative care within universal health coverage strategies, policies, plans and monitoring frameworks at the global, regional and national level.
- Civil society including patient groups need to be empowered and work with governments to raise peoples' awareness of their right to health, including palliative care, to thereby raise the demand for it.

13. Conclusion

Palliative care is a needed and essential health care service and a human right for adults and children living with, and dying from, life-limiting conditions. It should be a central component of any health care system and included within Universal Health Coverage schemes. The implementation of comprehensive Universal Health Coverage schemes could significantly increase access to quality hospice and palliative care for all those in need.

Adults and children with life-limiting illness, through to the end of life, and their families, should be able to access the palliative care services that they need without entering into financial hardship. In addition, the government, through whatever form of Universal Health Coverage it decides, should be responsible for providing quality palliative care services for their populations, and in particular ensuring that the most poorest and marginalised are not left out of pocket or financially destitute by accessing the care that they need.

Comprehensive hospice and palliative care services for adults and children must be included within Universal Health Coverage schemes, policies, implementation plans and monitoring frameworks. There needs to be improved availability and accessibility of hospice and palliative care services for adults and children, including access to medications for pain management and access to services in all settings where it is needed, including the home.







Palliative care in South Africa

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About the Worldwide Hospice Palliative Care Alliance

With our organisational members in over 70 countries, we provide a global voice on hospice and palliative care.

The Worldwide Hospice Palliative Care Alliance (WHPCA) is an international non-governmental organisation focusing exclusively on hospice and palliative care development worldwide. We are a network of national and regional hospice and palliative care organisations and affiliate organisations.

We believe that no-one with a life-limiting condition, such as cancer or HIV, should live and die with unnecessary pain and distress. Our vision is a world with universal access to hospice and palliative care. Our mission is to foster, promote and influence the delivery of affordable, quality palliative care.

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