



# Palliative care, COVID-19 and Universal Health Coverage

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## **Author Information**

Claire Morris, Worldwide Hospice Palliative Care Alliance

Julia Downing, International Children's Palliative Care Network

Joan Marston, Palliative Care in Humanitarian Aid Situations & Emergencies

Stephen Connor, Worldwide Hospice Palliative Care Alliance

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Photo credit on front page: Palliative care assistant visits woman in Narayanganj City Corporation, Bangladesh. BSMMU/WHPCA project funded by UK AID Direct.

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Coordinator visit at Narayanganj City Corporation, Bangladesh - WHPCA/BSMMU project funded by UK AID Direct

# 1

## Executive Summary

*“No one should face financial, geographical or cultural barriers to access to essential COVID-19-related services, including testing, treatment, palliative care and vaccines, once they become available.”*

[UHC2030 Report on State of Commitments to Universal Health Coverage, Synthesis 2020<sup>1</sup>](#)

The importance of palliative care in the response to COVID-19 and as a crucial part of the spectrum of essential health services within Universal Health Coverage is well recognised (See appendix 3). However, despite various policy commitments globally and nationally, there is concern that palliative care is not being integrated into COVID-19 responses, that essential palliative care services are being disrupted for adults and children with pre-existing conditions and that people are experiencing avoidable serious health-related suffering as a result.

This report highlights the findings of a survey in June 2020 of the membership and partners of the Worldwide Hospice Palliative Care Alliance, the International Children’s Palliative Care Network and Palliative Care in Humanitarian Aid Situations and Emergencies. The report focusses on five areas:

1. Access to palliative care. 2. Government integration of palliative care. 3. Financial sustainability of palliative care organisations 4. Universal Health Coverage and palliative care and 5. Partnerships for palliative care. A summary of findings can be seen in Box 1.

<sup>1</sup> UHC2030 (2020) Report on State of Commitments to Universal Health Coverage, Synthesis 2020

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## Box 1

### **Executive summary of findings based on respondents reports**

#### **1. ACCESS TO PALLIATIVE CARE**

- Palliative care services for adults and children with pre-existing palliative care needs are being disrupted
- People with COVID-19 are not getting the palliative care they need
- Vulnerable groups, including migrants and refugees, may be particularly at risk of not accessing palliative care

#### **2. GOVERNMENT INTEGRATION OF PALLIATIVE CARE**

- Many governments are not integrating palliative care into the COVID-19 response
- Most governments are not financing palliative care as part of their COVID-19 response

#### **3. FINANCIAL SUSTAINABILITY OF PALLIATIVE CARE ORGANISATIONS**

- Most palliative care organisations are concerned about their financial sustainability

#### **4. UNIVERSAL HEALTH COVERAGE AND PALLIATIVE CARE**

- Only half of respondents reported that palliative care was part of their country's Universal Health Coverage scheme

#### **5. PARTNERSHIPS FOR PALLIATIVE CARE**

- Organisations whose primary focus is not palliative care (e.g. older people groups, health care professionals' organisations) have been supporting the integration of palliative care in the response

This report provides recommendations to governments to integrate palliative care into COVID-19 responses, train health care workers in palliative care and build back better through the integration of palliative care into health systems, including through Universal Health Coverage reforms. It is a moral imperative to ensure that adults and children are not experiencing avoidable serious health related suffering during the COVID-19 pandemic which could be alleviated through access to integrated and cost-effective palliative care.



AIC Litein Hospital, Photo courtesy of Kenyan Hospices Palliative Care Association

## 2

# Background

The COVID-19 pandemic has swept across the globe exposing the weaknesses in health systems to ensure prevention, promotion, treatment, rehabilitation, and palliative care services for populations. Globally, approximately 57 million people need palliative care annually, yet it is estimated that less than 12% of people who need it access it.<sup>2</sup> While there are numerous policy commitments by governments to ensure palliative care access, progress to ensure access is slow.<sup>3</sup> Palliative care improves the quality of life of people with serious illness and there is increasing evidence on the crucial importance of palliative care for people with severe COVID-19, including to address severe breathlessness.<sup>4</sup> People with pre-existing palliative care needs and those who are living with and dying from severe COVID-19 living in countries without integrated palliative care are vulnerable to avoidable serious health-related suffering. This report seeks to highlight the situation in regard to palliative care access, government integration of palliative care and Universal Health Coverage during the COVID-19 pandemic.

2 Global Atlas of Palliative Care. 2020. Available at: <https://bit.ly/3dESF4h>

3 UN Political Declaration on UHC, WHA resolution on COVID-19, Astana Declaration, UN Political Declaration on NCDS

4 Ting Ruth, Edmonds Polly, Higginson Irene J, Sleeman Katherine E. Palliative care for patients with severe covid-19 BMJ 2020; 370 :m2710

# 3

## Methods

The Worldwide Hospice Palliative Care Alliance (WHPCA), International Children’s Palliative Care Network (ICPCN) and Palliative Care in Humanitarian Aid Situations & Emergencies (PALCHASE) held a survey open to its members and partners entitled ‘Palliative care, Universal Health Coverage and COVID19’. We received 90 responses between 17th and 29th June 2020 from 40 countries (see appendix 2). Quantitative and qualitative analysis was undertaken of the data to produce this report.<sup>5</sup>

This report also includes case studies and stories from providers and people living with palliative care needs globally.



Busia Hospice. Photo courtesy of Kenyan Hospices Palliative Care Association

<sup>5</sup> Limitations of the survey include that it is a snapshot during an evolving pandemic where situations are rapidly changing. In addition, respondents from the same country answered questions differently about their country situation. This is unsurprising given that some questions are subjective, and some questions are dependent on acquiring information which may not be accessible. In addition, people are responding from different locations, institutions etc within the country. Further research is required to validate the findings.

# What we found

## 4.1 Access to palliative care

Palliative care improves the life of people living with serious conditions such as cancer, HIV, organ failure, neurological conditions and dementia, across the lifespan. It is crucial to ensure quality care from diagnosis until the end of life. It provides physical, psychological, social and spiritual support for the person who needs palliative care and their family members and carers. It is about ensuring dignified, compassionate and individualised care based around a person's needs and what they want. Palliative care services are delivered where the person is, and where the person wants to be, whether that is the home, community, hospices, care homes or hospitals.

The COVID 19 pandemic creates many challenges for palliative care delivery. Firstly, people living with pre-existing palliative care needs and conditions such as those highlighted above are particularly vulnerable to COVID-19. Ensuring the maintenance of palliative care services for those people is crucial, especially as many are vulnerable, marginalised and unable to travel.

Our survey found that:

### **Palliative care services for adults and children with pre-existing palliative care needs are being disrupted**

Over 75% of respondents reported that delivery of palliative care services for adults and children with pre-existing palliative care needs (e.g. Non-COVID-19) had been severely or moderately disrupted as a result of COVID-19. These respondents came from 32 countries (See Fig 1).

Figure 1.

To what extent has COVID-19 disrupted the delivery of essential palliative care services to adults and children with pre-existing palliative care needs in your country (eg Not COVID-19 patients)

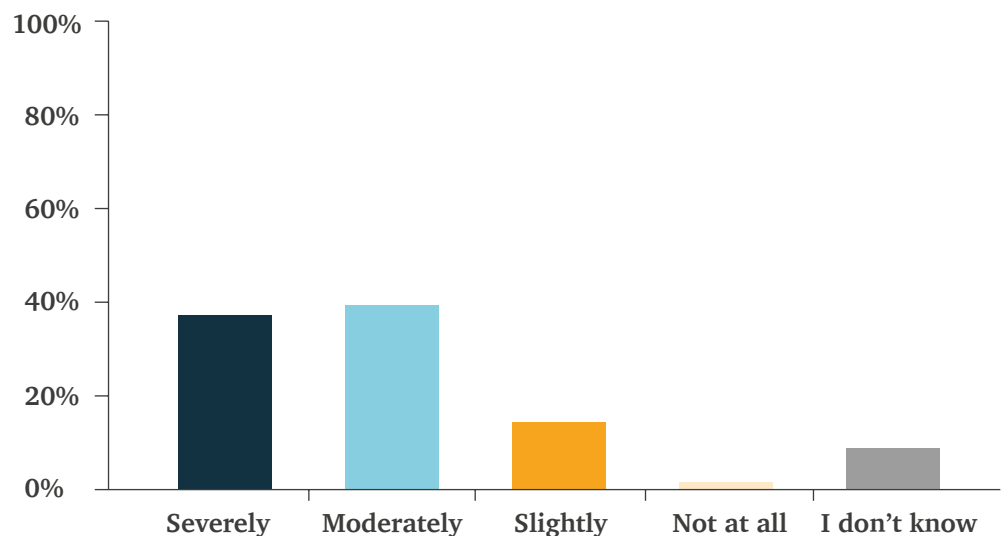




Table 1: Countries where respondents reported severely disrupted or moderately disrupted palliative care services<sup>6</sup>

Reported severely disrupted palliative care services	Reported moderately disrupted palliative care services
India, Uganda, Philippines, Bangladesh, Zimbabwe, Tanzania, Nigeria, Cameroon, Iran, Ecuador, Belgium, Macedonia, Portugal	South Africa, Germany, Ethiopia, Thailand, Canada, Zambia, Malaysia, UK, Egypt, Malawi, India, Mexico, Australia, Kenya, Pakistan, Nigeria, Korea, Indonesia



PPE being provided to health care professionals at the Catherine McCauley Hospice and Palliative Care Centre, Kenya. Photo courtesy of the Kenyan Hospices Palliative Care Association

### People with COVID-19 are not getting the palliative care they need

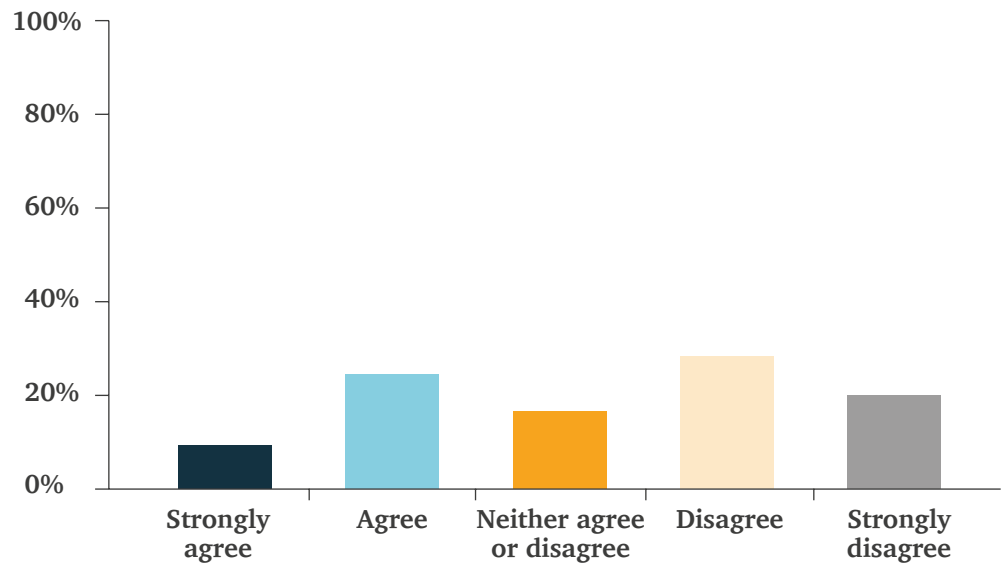
The survey requested respondents to report on whether they agreed that people with COVID-19 in their country were getting the palliative care that they need. 49% of respondents either strongly disagreed or disagreed that people with COVID-19 were getting the palliative care that they need, with only 33% of respondents strongly agreeing or agreeing that people with COVID-19 were getting the palliative care that they need (See Fig 2).

Respondents who strongly disagreed that people with COVID-19 were getting the palliative care they needed were from Bangladesh, Cameroon, Ecuador, Honduras, India, Indonesia, Iran, Kenya, Korea, Mexico and the UK.

<sup>6</sup> Where respondents from the same country answered differently, the responses were added up and the country was placed where the majority of respondents had reported.

Figure 2.

Please indicate whether you agree or disagree with the following statement: People with COVID-19 who need palliative care in my country are getting the palliative care that they need



The major barriers reported by respondents in providing palliative care to adults and children with COVID-19 were:

- 1) Inability to undertake home visits (64%),
- 2) Lack of health care workers trained in palliative care (59%) and
- 3) palliative care not integrated in the health care system (53%).

However, many organisations are working hard to address the barriers and ensure that people can receive the palliative care they need, covering physical, psychological, social and spiritual issues and to ensure that health care workers, carers and people with palliative care needs are protected.

*“Palliative Care has not been mentioned in any forum discussing COVID-19 except those minority who are actively involved with palliative care provision.”*

Respondent from Bangladesh

*“Bulgaria does NOT have palliative care specialty, no specialists with diploma in palliative care, only 1 clinical pathway for palliative patients, very underfinanced unfortunately and only few hospitals and hospices are using it.”*

Respondent from Bulgaria

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Mr X's story from Korail, Bangladesh

*Mr. "X" is a 67-year-old male patient suffering from COPD. Compassionate Korail Project supporting him for past three years to alleviate his sufferings. He has been receiving necessary medicine, home care, monthly food packs and other palliative care support from the project.*

*He and his family is very satisfied about care and support of the project. His wife mentioned, "Usually people do not come to visit him or like to sit beside him due to his breathlessness. My husband feels very good when you (PCA or other team member) come to visit, sit beside him, and provide care".*

*This poor guy is a street beggar and used to manage living cost by begging in the Korail slum. But now his earning dropped about 70% due to COVID 19 Pandemic situations. His wife used to work as a house maid and now her work has also gone! Before COVID Pandemic his son sometimes supported them but now he also lost his earning. Even in monsoon time due to rain he couldn't go for begging on daily basis. For last three months he is unable to pay house rent and struggling to manage minimum living cost! He is usually a hardworking person but due to age and physical conditions he can't do other works for earning.*

*During a conversation, he said, "During this corona period if your team (project) wouldn't have given me the extended food pack (double in quantity than previous) and necessary medicines, I won't be alive yet. May Allah bless you!"*

*Struggle has always been present in his life, however this COVID pandemic gave him the most miserable experience of life time.*

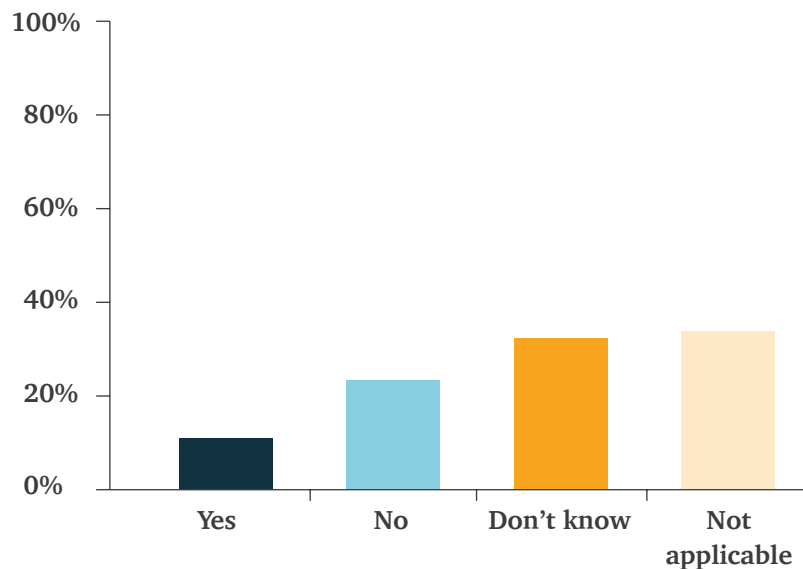


Patient consultation over a mobile phone – Narayanganj City Corporation, Bangladesh. Photo courtesy of BSSMU and WHPCA. Project supported by UK AID Direct.

### **Vulnerable groups, including adult and child refugees, may be particularly at risk of not accessing palliative care.**

Our survey showed that only 11% of respondents thought that adults and children in refugee camps are receiving palliative care. More research needs to be done to look at access issues in refugee camps and humanitarian situations. However, this is aligned with the view and work of PalCHASE and others around the limited availability of palliative care in these settings. (See Fig 3)

**Figure 3.** Are adults and children in refugee camps in your country receiving palliative care?



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## 4.2 Government integration of palliative care

Hospice and palliative care has grown outside of many national health systems, being led and delivered by communities and NGOs and financed through philanthropic and community funding. The recent global atlas on palliative care showed that only 64 countries had palliative care integrated into their health system. While this figure gives some indication of government engagement and integration within health systems, the figure does not provide further information on the extent to which palliative care is publicly financed, delivered or the responsibility of the state. As an example, the UK falls into the category of fully integrated and yet much palliative care is provided in the country by NGOs such as hospices, financed by community fundraising.

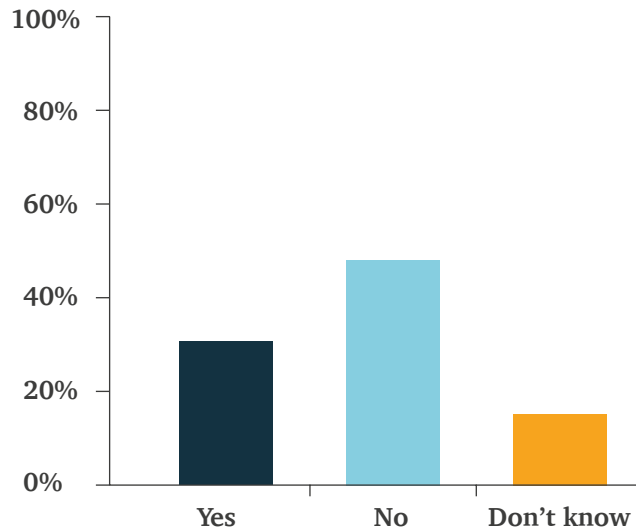
WHO guidelines as well as the WHO resolution on COVID-19 clearly recommend and provide strong technical assistance on the inclusion of palliative care within COVID-19 responses. Yet, there is little monitoring around the extent to which this guidance is actually followed.

In our survey, we wanted to find out the extent to which governments are including palliative care in their COVID-19 responses and the extent to which they were supporting community delivery of palliative care. We found that:

### **Many governments are not integrating palliative care in the COVID-19 response**

48% of respondents reported that their governments are not including palliative care in their COVID-19 response plan and 17% did not know. 25% of respondents stated that palliative care was being included in government national COVID-19 response. 22% of respondents reported that governments were working with palliative care units to support health care workers. Unfortunately, less than 15% of respondents reported that governments were training health care workers in palliative care skills and less than 14% of respondents agreed that governments were working to ensure access to essential palliative care medicines. Despite the lack of government support of palliative care, 79% of respondents believed that COVID-19 was an opportunity for governments to understand the importance of palliative care as part of a strong health system. (See Fig 4)

**Figure 4.** Is your government including palliative care in its COVID-19 response?



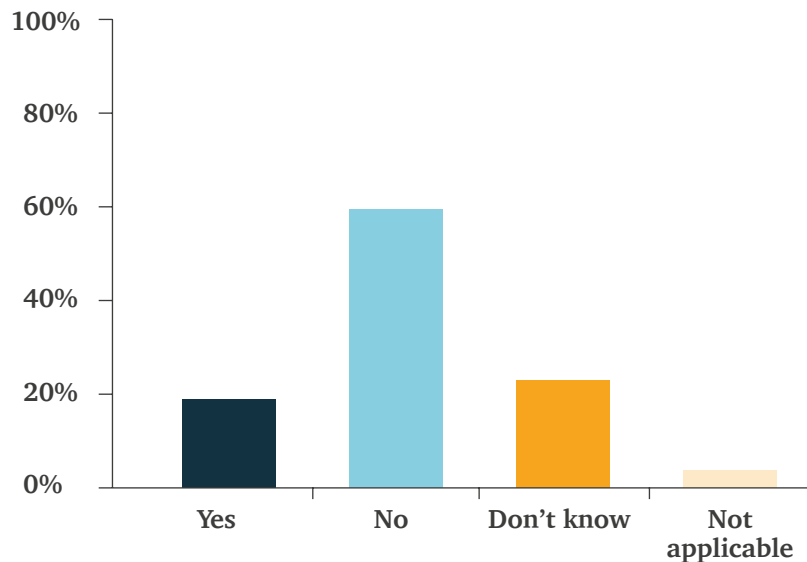
*“Our recently launched Home based care for COVID 19 doesn't include palliative care”*

Respondent from Kenya

### Most governments are not financing palliative care as part of their COVID-19 response

Less than 19% of respondents said that governments had provided government financing for palliative care expertise or services in the COVID-19 response. 57% of respondents stated that no government financing had been provided. Interestingly, almost 30% of respondents said that the COVID-19 pandemic had strengthened their relationship with government. (See Fig 5).

**Figure 5.** Has your government provided funding for palliative care expertise or palliative care services in the COVID-19 response?



*“There aren’t policies for palliative care in Brazil in the national level. In local level there are public policies. But the funding is restricted.”*

*Respondent from Brazil*

*“Major challenges we face are • Healthcare system’s resistance to change in the context of poor understanding and lack of awareness about palliative care • Also the health system overburdened by COVID-19 is not willing to listen • Pushback from the healthcare agencies as all they want to talk about is prevention and cure, and not adjunct management in place of ventilation or end of life care • Palliative care is not yet part of government’s COVID-19 strategy • Attitude of the health system is focused on diseases, not health related suffering.”*

*Respondent from India*

*“When I was diagnosed with cancer of the breast, I had no money to pay for more medical tests and the operation until Hospice Jinja came to my rescue. They covered the costs. I urge the government to provide all cancer care services free of charge to Ugandans because many poor people cannot afford the high costs involved”*

**Sakina Nandobyia**

Jinja, Uganda



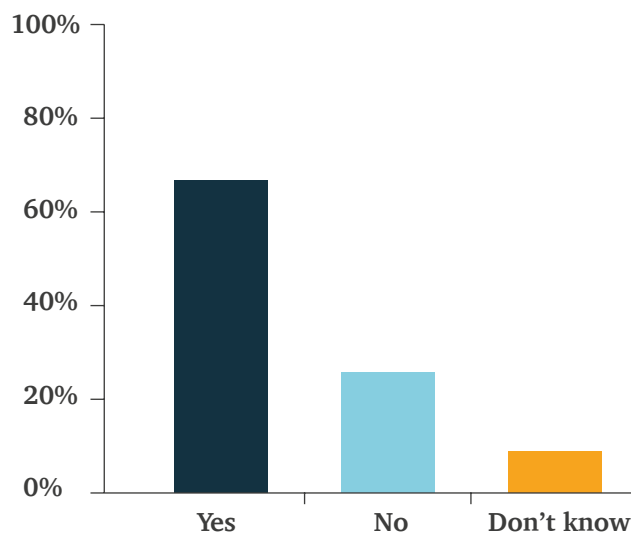
**whpca**  
West African Palliative Care Association

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## 4.3 The financial sustainability of palliative care organisations

The majority (65%) of palliative care organisation reported that they are concerned about the financial sustainability of their organisation. (See Figure 6)

**Figure 6.** Are you concerned about the financial sustainability of your organisation?



When asked how COVID-19 has affected their income, they responded with a number of issues, including:

- 1. Reduction in donations and funders** – Many respondents reported a reduction in income which they attributed to the weakened financial situation of their donors. In addition, they reported the challenges of undertaking public fundraising during the pandemic.
- 2. Diversion of resources to COVID-19** – Concerns were raised that resources were being diverted to COVID-19. This concern seems to suggest that palliative care was not being included within that diversion.
- 3. Reduction in paying patients** – In organisations where user fees were applicable, the organisations noted that patients were unable to pay or that patients were not coming to the service due to their fear of COVID-19.

*“Losing £500k per quarter in fundraising and retail income. Though shops will re-open, many events will be a long time returning if at all”*

*Respondent from a children’s hospice, UK*

*“There is a deficit in the running cost of palliative care services. No home visits as there is funding gap as most funds come from outside Malawi which are heavily affected by COVID-19.”*

*Respondent from Malawi*



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## 4.4 Universal Health Coverage and palliative care

Palliative care is part of the spectrum of essential health services as defined within the WHO definition of Universal Health Coverage (see box 2). The importance of strong health systems and Universal Health Coverage has been repeatedly reiterated during the pandemic. COVID-19 have exposed the flaws in health systems.

### Box 2

#### WHO definition of universal health coverage<sup>7</sup>

Universal health coverage is defined as ensuring that all people have access to needed health services (including prevention, promotion, treatment, rehabilitation and palliation) of sufficient quality to be effective while also ensuring that the use of these services does not expose the user the financial hardship.

While there are numerous UN commitments to palliative care as part of Universal Health Coverage including within the UN Political Declaration on Universal Health Coverage, there is little tracking of progress in relation to access to palliative care. This is partly due to consistent challenges with getting a used, tested and quality indicator which has been raised as an issue by the World Bank and WHO<sup>8</sup> and the WHPCA in their report on Palliative Care and Universal Health Coverage amongst many others. There is therefore concern that palliative care is not being integrated into Universal Health Coverage reforms in a way that means that people can access palliative care.

#### Our survey found that:

- **Less than half of respondents (48%) reported that palliative care was part of their country's Universal Health Coverage scheme.**
- 38% of respondents stated that palliative care was not part of their countries Universal Health Coverage.
- 14% of respondents either did not know or did not believe it was applicable.

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<sup>7</sup> [https://www.who.int/healthsystems/universal\\_health\\_coverage/en/](https://www.who.int/healthsystems/universal_health_coverage/en/) (Accessed December 1 2020)

<sup>8</sup> WHO and World Bank Group (2014) Monitoring progress towards universal health coverage at country and global levels: Framework, measures and targets

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## HELENA DAVIES' STORY

### “Shielding” – essential but isolating

*My name is Helena Davies I am a 59 year old woman with a severe complex auto inflammatory condition which affects many of my systems including nerves and muscles meaning that I depend upon a motorised wheelchair and am on multiple medications. I am in the top 5% of the “extremely vulnerable” group and have been shielding at home with my husband, a GP, since the start of the pandemic in March 2020. In the UK, I can access palliative care through our version of Universal Health Coverage.*



*Before COVID struck I had been living with severe health related suffering for which I have been receiving specialist palliative care (PC) at home for over 10 years. Their input has varied depending on my needs but I always know they are only a phone call away. This is, and always has been, tremendously reassuring. Their input has been particularly critical in terms of pain management and psychosocial support.*

*COVID led to many immediate changes in my life and that of my family. Previously cared for at home by a paid carer we agreed that due to the COVID risk, my husband, (a GP with 25 years in practice), had to stop working and become my carer. His continuing to go to the practice every day placed me at unacceptably high risk. Since March we have been shielding meaning our only social contact even when not in lockdown is in the garden socially distanced. My children, although grown, were (and still are) unable to come home or give me and my husband their wonderful hugs - the vital expressions of human connection and love. Our home became filled with uncertainty, isolation and anxiety, having previously been a cheerful, bustling unofficial ‘drop in refuge’ for many in need. It necessarily marches to a setting of carefully planned infection prevention routines and the shielding requires a*

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*withdrawal from the real world. Thank goodness for Zoom and FaceTime!*

*Palliative care has continued for me over this time through the wonderful professional services of my consultant and social worker. Between them, the impact of some additional challenges I have faced, (including for example damage to my shoulder after a fall, nerve pains in my feet), on top of the extreme isolation, have been managed. Inevitably the longevity of shielding and the uncertainty about how long it will continue, (our geographical area is now back in lockdown so we cannot currently even have visitors in the garden), have taken their toll on my own mental health and I am due to “see” the psychologist from the PC team for additional support. My usual care (complex pain needs, PEG feeding tube, intravenous treatments, topical patches and my daily subcutaneous injections) has been able to continue but this would have been much more difficult to manage had my husband not been a GP.*

*I also continue to have additional PPE protected distanced input from my paid carers supporting me and my husband. All this care has been provided free by the NHS. We are the lucky ones. Many in the UK do not receive the standard of PC we have, and continue to receive during the pandemic. Through my work with the WHPCA I am aware that most of those living in LMIC countries have no provision of holistic care, they may not even get 5mg of morphine.*

*The need for palliative care is greater than ever in the context of covid19. We must not be forgotten or left behind.*

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## 4.5 Partnerships for palliative care

It has long been recognised that the integration of palliative care into broader health and social care responses and a greater demand for palliative care outside of the palliative care community is needed. The devastating COVID-19 pandemic may have provided opportunities for increasing partnerships with broader health and development agencies taking a greater leadership role on ensuring access to palliative care.

**Our survey found that:**

- **Organisations whose primary focus is not palliative care (e.g. older people groups, health care professionals' organisations) have been supporting the integration of palliative care in the response.**
- 47% of respondents reported that non-palliative care specific NGOs, academic institutions and others supported greater access to palliative care as part of the COVID-19 response.
- The groups or organisations that were most engaged in supporting palliative care were
  - a) Health care workers/professional organisations (50%),
  - b) Community health or caregiver groups (36%),
  - c) Older people groups/care homes (23%) and
  - d) Children's groups/orgs (23%).
- The least engaged were:
  - a) Access to medicines groups (12%),
  - b) Dementia groups (17%),
  - c) Women and girls groups (18%) and
  - d) NCDs groups (18%).



Foodpack distribution during COVID-19 pandemic - WHPCA/BSMMU project funded by UK AID Direct

## 5

# Conclusion

This report reinforces concerns about the integration of palliative care in COVID-19 responses and the maintenance of existing palliative care services for those with pre-existing health care needs. Government support and the integration of palliative care into COVID-19 responses is perceived to be low, with little evidence of financial support or contributions to palliative care integration or service delivery. The sustainability of civil society palliative care services is in doubt. Greater partnership working and other civil society groups taking a greater leadership role in holding governments accountable for the availability and accessibility of palliative care services during the COVID-19 pandemic and beyond is crucial. Coordinated action to integrate palliative care services into health systems and the COVID-19 response with proper financing could prevent avoidable serious health related suffering around the world for the millions of people with palliative care needs.

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# 6

## Recommendations for government

In order to ensure that people with serious illness and those with severe COVID-19 have the best quality of lives and their family members and carers are supported, it is crucial that palliative care is integrated in immediate COVID-19 responses as well as longer term integration into health systems and Universal Health Coverage reforms. Our recommendations to government are:

- **INTEGRATE PALLIATIVE CARE INTO THE COVID-19 RESPONSE** – In line with the WHA Resolution on the COVID-19 Response, ensure that palliative care is included in COVID-19 response plans and is adequately financed.
- **ENSURE THAT THE MOST VULNERABLE WITH PALLIATIVE CARE NEEDS, INCLUDING OLDER PEOPLE, REFUGEES AND CHILDREN, ARE NOT LEFT BEHIND.**
- **TRAIN HEALTH CARE WORKERS IN PALLIATIVE CARE** – Ensure health care workers are trained in palliative care and palliative care is integrated into health care workers curricula at all levels as well COVID-19 specific training.
- **ENGAGE WITH CIVIL SOCIETY PROVIDING PALLIATIVE CARE TO ADDRESS SUSTAINABILITY ISSUES** – Options may include to undertake a risk assessment on the impact on people’s lives and health systems of civil society palliative care organisations collapsing due to financial insecurity.
- **ENSURE PALLIATIVE CARE INCLUSION IN UNIVERSAL HEALTH COVERAGE INCLUDING PUBLIC FINANCING AND INDICATORS TO TRACK PROGRESS** – Assess and address gaps in palliative care as part of UHC reforms and systems.

# Appendices

## Appendix 1: Survey questions

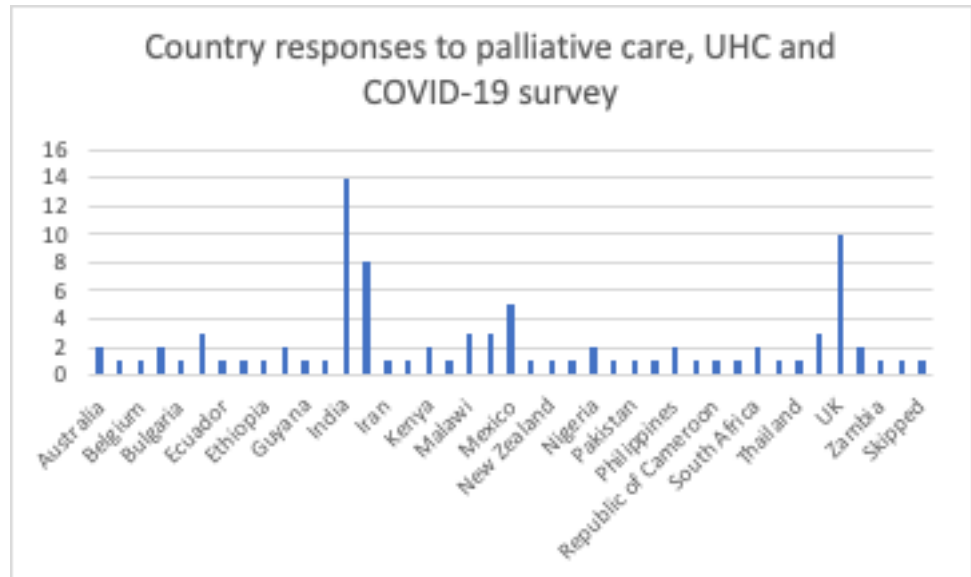
1. Name
2. Organisation
3. Country
4. Email
5. To what extent has COVID-19 disrupted the delivery of essential palliative care services to adults and children with pre-existing palliative care needs in your country (e.g. Not COVID19 patients)
  - Severely / Moderately / Slightly / Not at all / I don't know
6. Please describe the main challenges your country is facing in providing palliative care to adults and children with pre-existing palliative care conditions (Not COVID-19 patients) and how you are overcoming these challenges?
7. Please indicate whether you agree or disagree with the following statement: People with COVID-19 who need palliative care in my country are getting the palliative care that they need.
  - Strongly agree / Agree / Neither agree nor disagree / Disagree / Strongly disagree
8. Please describe the main challenges your country is facing in providing palliative care to adults and children who have COVID-19 and need palliative care?
  - Lack of personal protective equipment
  - Staff refusal or reluctance to deliver care
  - Lack of funding
  - Inability to make home visits
  - Lack of training on COVID-19 for health care workers
  - Lack of access to people with COVID-19
  - Staff being moved to other health care departments /areas
  - Lack of volunteers
  - Lack of health care workers trained in palliative care
  - Palliative care not integrated in health care system
  - Other (please specify)
9. Are health-care workers engaged in palliative care in your country adequately equipped with the appropriate PPE?
  - Fully /Partly /No /I don't know

- 
10. Are adults and children in refugee camps in your country receiving palliative care?
    - Yes / No / Don't know / Not applicable
  11. Is your government including palliative care in its COVID-19 response?
  12. How is your government including palliative care in its -response? (tick all that apply)
    - Palliative care is included in national COVID19 Response plan
    - Government are financing palliative care as part of COVID19 response
    - Government are stockpiling and/or ensuring access to palliative medications
    - Government are training health care workers in palliative care
    - Government are training palliative care workers in COVID19
    - Government are providing personal protective equipment to palliative care workers
    - Government are working with palliative care organisations to support health care workers
    - It isn't
    - I don't know
    - Other (please specify)
  14. Has your government provided funding for palliative care expertise or palliative care services in the COVID-19 response?
    - Yes / No / Don't know / Not applicable
  15. How has COVID-19 impacted on your organisational relationship with government?
    - Strengthened the relationship
    - There is no difference
    - Weakened the relationship
    - Not applicable
  16. Are you concerned about the financial sustainability of your organisation? w
    - Yes / No / Don't know
  17. In what ways has COVID-19 impacted the financial sustainability of your organisation or services?
  18. Do you foresee that your organisation will still be operating in 6 months if more funding is not accessed? w
    - Yes / No / Don't know / Not applicable
  19. If your organisation will not be operating in 6 months, what impact will that have on adults and children with palliative care needs in your country?
  20. Does your country have palliative care as part of Universal Health Coverage?
    - Yes / No / Don't know / Not applicable
  21. Have other organisations including NGOs or academic partners in your country supported greater access to palliative care as part of the COVID-19 response?
    - Yes / No / Don't know



- 
22. Please give details of any group or organisations you have been working together with who have supported palliative care asks around the COVID-19 response in your country? (Tick all that apply)
- Universal Health Coverage groups
  - Women and girls groups
  - Disability groups
  - Mental health groups
  - NCDs groups
  - Dementia groups
  - HIV groups
  - Community health or caregiver groups
  - Patients groups
  - Access to medicines groups
  - Health workers or health professional groups
  - Older people groups or care homes
  - Humanitarian organisations
  - Children's groups or organisations
  - Other (please specify)
23. Have you developed new or strengthened partnerships with NGOs, academia, patient groups, community groups or others during the COVID-19 pandemic?
- Yes / No / Don't know
24. Are there particular messages, communications or advocacy tactics that have helped your government or key actors, such as funders and providers, understand the importance of palliative care in the COVID-19 response in your country or region?
25. What are the major challenges you have faced in communicating why palliative care must be included in the COVID-19 response?
26. Have you engaged the media in relation to palliative care as part of the COVID-19 response? (please give any detail)
27. Please explain if you have been working with people with palliative care needs as advocates to raise the importance of access to palliative care during the COVID-19 pandemic?
28. Do you think that COVID-19 provides an opportunity for your government to understand the importance of palliative care as part of a strong health system?
- Yes / No / Don't know
29. Which aspects of palliative care have been most utilised in your response to the pandemic? (e.g. communications skills, end of life care, spiritual support, psychological support, symptom control)?
30. What do you need from national palliative care organisations to support you during these times?
31. What do you need from the WHPCA, ICPCN and PALCHASE to support your work to integrate palliative care into the COVID-19 response now and to use this tragic opportunity to mainstream palliative care into health systems in the future?

## Appendix 2: Number of individuals who responded to survey from each country



## Appendix 3: Inclusion of palliative care in UN resolutions and guidance relating to COVID-19

Document type	Title	Weblink
WHO resolution	COVID-19 Response	<a href="https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_R1-en.pdf">https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_R1-en.pdf</a>
Technical guidance	Clinical management of COVID-19	<a href="https://www.who.int/publications/i/item/clinical-management-of-covid-19">https://www.who.int/publications/i/item/clinical-management-of-covid-19</a>
Technical guidance	Maintaining Essential Health Services: Operational Guidance for the COVID-19 context interim guidance	<a href="https://www.who.int/publications/i/item/WHO-2019-nCoV-essential-health-services-2020.1">https://www.who.int/publications/i/item/WHO-2019-nCoV-essential-health-services-2020.1</a>
Technical guidance	Preventing and managing COVID-19 across long term care services	<a href="https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1">https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1</a>
Technical guidance	Operational planning guidelines to support country preparedness and response	<a href="https://www.who.int/publications/i/item/draft-operational-planning-guidance-for-un-country-teams">https://www.who.int/publications/i/item/draft-operational-planning-guidance-for-un-country-teams</a>
Technical guidance	WHO COVID-19 Essential Supplies Forecasting Tool Overview	<a href="https://www.who.int/docs/default-source/coronaviruse/who-2019-ncov-tools-essential-forecasting-2020-3-eng.xlsx?sfvrsn=e14d78b7_1&amp;download=true">https://www.who.int/docs/default-source/coronaviruse/who-2019-ncov-tools-essential-forecasting-2020-3-eng.xlsx?sfvrsn=e14d78b7_1&amp;download=true</a>
Further resources on palliative care and COVID-19	Varied	<p>International Association for Hospice Palliative Care - <a href="http://globalpalliativecare.org/covid-19/">http://globalpalliativecare.org/covid-19/</a></p> <p>International Children’s Palliative Care Network – <a href="http://www.icpcn.org">www.icpcn.org</a></p> <p>Palliative care in Humanitarian and Emergency Situations <a href="https://www.phpc.cam.ac.uk/pcu/palchase/coronavirus-and-palliative-care/">https://www.phpc.cam.ac.uk/pcu/palchase/coronavirus-and-palliative-care/</a></p> <p>Worldwide Hospice Palliative Care Alliance – <a href="http://www.thewhpc.org/covid-19">http://www.thewhpc.org/covid-19</a></p>

