



**LEAVE NO ONE BEHIND**

**EQUITY IN ACCESS TO PALLIATIVE CARE**

A REPORT FOR  
**WORLD HOSPICE  
PALLIATIVE CARE  
DAY 2021**



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PHOTO: courtesy Chuck Russell Two Worlds Cancer Collaboration

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# INTRODUCTION

Palliative care improves the lives of people with serious illness and alleviates avoidable suffering. People with life-threatening or incurable health conditions or serious health related suffering require palliative care to manage their physical, psychological, social and spiritual issues. Palliative care has been recognised by the World Health Organisation and governments around the world as a fundamental part of Universal Health Coverage and health systems. It has also been recognised as a crucial aspect of the human right to health.

Yet palliative care is one of the most inequitable areas of healthcare. There is strong evidence that people with reduced power or marginalised status are less able to access the palliative care they need. Across countries, people who live in low and middle income countries have a greater need for palliative care but less access to palliative care services. 76% of the people who need palliative care live in low and middle income countries, yet there are few palliative care services. Inequities exist within countries too. People have less access to palliative care as a result of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status.

The root causes of health inequities are driven by the social determinants of health. Where we live, how we live and where we work all impact on our access to health services and our health outcomes. While efforts to address palliative care inequities must look at how palliative care services are provided and to whom, it is important that palliative care advocates and providers situate themselves in the larger picture. There is a role for all of us to address the root causes which drive health inequity such as poverty and discrimination.

This report discusses the current evidence on some inequities in palliative care and highlights where palliative care providers and advocates are working to address these inequities. The report also concludes on what more needs to be done. We hope that this report is used to initiate further conversations and sharing of work being done to make palliative care available to all who need it – wherever they live, whoever they love and whatever their age or background.

**“without question the most disfiguring inequity in health care today”**

Richard Horton, Editor of the Lancet on the launch of the Lancet Commission on Palliative Care and Pain Relief

# PALLIATIVE CARE INEQUITIES ACROSS COUNTRIES



## **Palliative care access is inequitable across countries**

If you live in a low and middle income country (LMIC), you are less likely to access palliative care. 76% of people who need palliative care live in low and middle income countries (43 million people)<sup>[1]</sup>. Yet, availability and access to palliative care services in LMICs is often extremely limited. Of the 25,000 palliative care services identified globally, only 30% are in LMIC.<sup>[2]</sup> Those who are born in low and middle income countries are more likely to experience pain and distress as a result of serious illness or serious health-related suffering than those who live in high income countries due to lack of access to palliative care services.

## **Access to pain treatment is inequitable across countries**

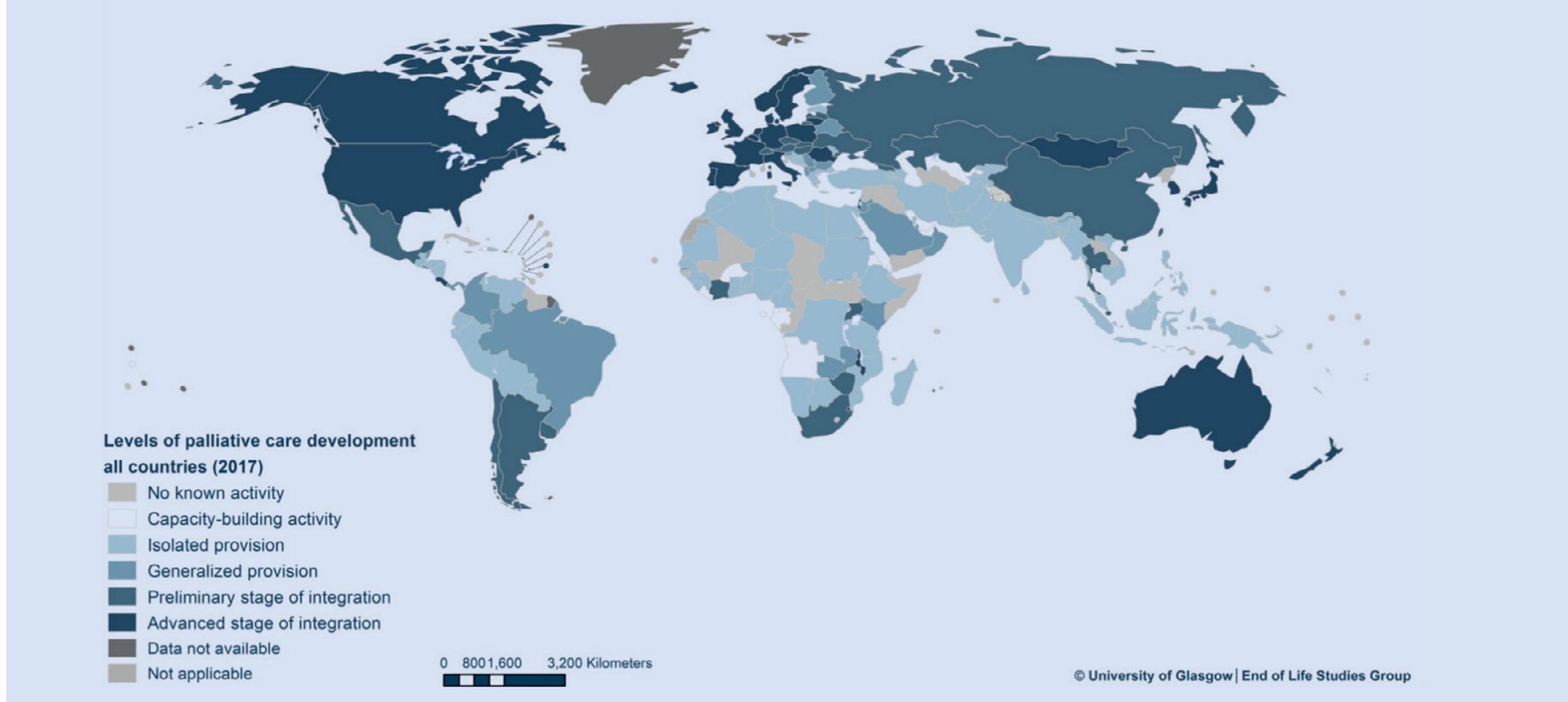
People are less likely to access the pain treatment they need if they live in low and middle income countries. Morphine-equivalent opioids are an important aspect of pain treatment for people living with serious illness. Of the 298.5 metric tonnes of morphine-equivalent opioids distributed in the world per year, only 0.1 metric tonne is distributed to low-income countries.<sup>[3]</sup> This is despite the fact that the greatest need for palliative care and pain treatment is in low and middle income countries.

## **Palliative care inequities are a result of government policy, financing and a lack of palliative care trained healthcare workers.**

There are multiple causes of inequitable access to palliative care and pain treatment across countries. In low and middle income countries, health systems are not adequately financed and palliative care is often not financed as part of the health system. Palliative care is often not integrated into health policies and when palliative care policies exist, they may not be implemented. Health care workers and community carers are not trained in palliative care and pain treatment as palliative care and pain treatment is often not part of health training curricula.

## **Many countries are closing the gap in equity to palliative care**

Despite the issues in equitable access, many civil society organisations in LMICs are working with their governments to increase access to palliative care. Approaches in-country which incorporate policy, education, medications access, financing, advocacy and accountability are demonstrating great results in building access. Yet, while palliative care is increasingly becoming available to people who need it, there is much more work to be done.



## Addressing inequities across countries

### Case study: National action: Malawi

Malawi has seen an upsurge in availability and quality of palliative care services over the previous two decades. From 2006-2011, Malawi went from being categorised as having isolated provision of palliative care to integrated palliative care services. Between 2006-2011, Malawi saw the greatest increase in morphine consumption (a proxy indicator for palliative care development) of any country in the world. One of the key factors that is behind Malawi's success in ensuring palliative care access is strong champions and local, national and international partnerships. Leadership within government and collaboration between government and national and local civil society has been key, as has the support of international funders.<sup>[4]</sup>

### Case study: Global commitments to palliative care as part of Universal Health Coverage

Universal Health Coverage (UHC) is one of the driving forces of global health today and a vital component of the SDGs. In 2015, all governments globally committed to work towards Universal Health Coverage, which includes palliative care, by 2030. In the High Level Meeting on UHC in 2017, this commitment was reiterated. The Lancet Commission on Palliative Care and Pain Relief<sup>[5]</sup> has recommended an essential package of palliative care services. Globally, civil society organisations continue to advocate for governments to reaffirm and maintain these commitments. At the same time, national and local advocates work to make the reforms a reality at the national level.

# OLDER PEOPLE

The current situation



PHOTO: Palliative care in Bangladesh: WHPCA/BSMMU

## Older people are less likely to access the palliative care that they need

Research shows that older people are more likely to have untreated pain, less access to palliative care and more information needs than younger people in many settings.<sup>[6],[7]</sup>

## Older people have specific palliative care needs

The specific palliative care needs of older people include issues such as management of frailty, disability and multi-morbidity, recognising the rising issue of dementia. The report by Hospice UK on inequalities in palliative care access highlighted the physical and social factors that also impact on older people including older women being more likely to live alone and the millions of homes for older people that are failing to meet basic standards.

**“If you people had not come to support and care for me and provided physiotherapy then I might not be able to walk and I would have died earlier.”**

71-year-old woman from Korail

## Many programmes are working to address inequities in access to palliative care for older people

In 2018, the United Nations Open Ended Working Group on Ageing made a strong call for the rights of older people to access palliative care and pain treatment.<sup>[8]</sup> There are many publications which seek to provide practical guidance on how to ensure equitable palliative care for older people in different settings.<sup>[9]</sup> Globally, palliative care providers are working to understand and address the particular needs of older people in their settings. Yet there is much to be done to address the inequity issues.

### Case study: Compassionate Korail: a BSMMU/WHPCA funded project

In the Korail Urban Settlement, there was no palliative care for people who needed it. In 2015, BSMMU and the WHPCA set up a project to support older people access palliative care. The project trained a team of palliative care assistants in the community to identify and provide essential care to older people. These assistants were supported by health professionals trained in palliative care from BSMMU. A 71-year-old woman from Korail, who was previously bedbound, said: “If you people had not come to support and care for me and provided physiotherapy then I might not be able to walk and I would have died earlier.”<sup>[10]</sup>



PHOTO: Palliative care in Bangladesh: WHPCA/BSMMU

# CHILDREN AND ADOLESCENTS



## Most children who need palliative care cannot access it.

ICPCN estimates that 21 million children globally need palliative care globally including 8 million with specialised needs.<sup>[11]</sup> The majority of children (>97%) who need palliative care live in low and middle income countries. Yet, in this context, palliative care services for children are rarely available.<sup>[12], [13]</sup> In high income countries, there are also significant barriers to access to children's palliative care. The result of the lack of access to children's palliative care is unnecessary pain and suffering for children with life-limiting illness and serious health related suffering and their families and carers.

**ICPCN estimates that 21 million children globally need palliative care**

PHOTO: courtesy Little Stars, Malaysia, Moonshine Agency

## Children have particular palliative care needs<sup>[14]</sup>

Children are not small adults and need care and communication to be appropriate for their age and developmental stage; they may have their own ideas, concerns and even solutions so involve the child in their health care decision making.

Children facing serious illness are vulnerable and depend on the adults around them to assess and manage their pain and other distressing symptoms to improve quality for the child and family.

Many children requiring palliative care are non-verbal or pre-verbal and extra attention needs to be paid to assessment and listening to the primary caregivers – they know the child best.

Children facing serious illness are still children and should have the right to education, the right to play and the right to be heard. Palliative care for children includes care for their mind, body and spirit and therefore upholds these rights.

Children must be protected from maltreatment and abuse; this includes protection from pain and suffering caused by hospitalisation, illness and procedural pain.

## There are programmes to increase equitable access to children's palliative care

Yet, while inequity in access to palliative care remains, there are great strides happening globally to make children's palliative care available to all who need it<sup>[15]</sup>.<sup>12</sup> From the global advocacy and education work of the International Children's Palliative Care Network to the programmatic work on the ground in countries from innovative projects in urban settlements in Bangladesh, beacon centres in sub-Saharan Africa, to the building of the first children's hospice in Norway, people are working to ensure that children with serious illness and palliative care needs are not forgotten.<sup>[16]</sup><sup>[17]</sup>



PHOTO: courtesy Chuck Russell Two Worlds Cancer Collaboration



“While we are working hard to ensure more equitable access to palliative care for children, there is much to do. Children cannot be left behind to suffer as we strive to make essential healthcare, including palliative care, available to all those who need it.”

Professor Julia Downing

# WOMEN

The current situation



## **Women are more likely to be the carers of people with serious illness.**

57 million people have palliative care needs worldwide annually. A conservative estimate suggests that there are 114 family carers supporting people with palliative care needs.<sup>[18]</sup> Evidence states that carers are more likely to be women and that women also do 50% more care than men.<sup>[19]</sup> Similar to other areas of health care, nurses and social workers in palliative care are more likely to be women. Women are providing the vast amount of care for people with serious illness as health care workers, in homes and in communities.

## **Women carers are often not adequately recompensed, supported, trained or equipped in their caring role.**

There is significant evidence around the absence of recompense, support, training and equipment for women carers around the world. There is also significant evidence on the impact on the health and well-being of women who are providing care for people with serious illness. Gender norms place women in the role of carer yet the systems are not in place to support them to do so both for their own well-being and for the well-being of those they are caring for.

Legal workshop on rights and palliative care, Narayanganj, Bangladesh - BSSMU and WHPCA funded by U.K. aid

## Women are treated and cared for differently than men towards the end of life and bear significant legal, economic and social consequences when they are widowed.

It is believed that more women access palliative care than men, potentially due to later presentation by men to health care providers. Yet it is also understood that women are treated and cared for differently than men when they access care. Men are more likely to get more aggressive treatment. Women's pain is more likely to be dismissed and under-treated. Women being abandoned by their partners during times of ill health are reported in many settings. In addition, the worries of women with palliative care needs relating to property rights, inheritance and their children's livelihoods are exacerbated when legal rights are either not understood, or where systems are biased towards the rights of men in relation to property and finance.

## Ensuring the voice of women is heard

There are many initiatives globally which are seeking to raise the voice of women, particularly as carers. UN Women, including at the Commission on the Status of Women, has long argued the need to recognise and address issues with unpaid care which largely falls on women. At the programmatic level, palliative care providers globally seek to ensure that women are supported, trained and equipped in their caring roles as well as seeking to increase the number of male carers.

**Evidence states that carers are more likely to be women and that women spend 50% more time providing care than men**

## Case study: Compassionate Narayanganj, Bangladesh

In 2018, the WHPCA with BSSMU University accessed UK government funding to develop the Compassionate Narayanganj project in Bangladesh, bringing palliative care to where there was none. A central component of the programme is to consider the particular issues of women and girls both as patients and carers. As part of this, the project ensures disaggregation of all data enabling analysis of issues that particularly affect women and girls. A legal workshop was held as part of the project to support women understand their rights, including in relation to property rights and inheritance. In addition, the project carefully considered the issue of women as carers and the role and potential of male carers in the community.



Legal workshop on rights and palliative care, Narayanganj, Bangladesh - BSSMU and WHPCA funded by U.K. aid

# PEOPLE LIVING IN POVERTY AND DEPRIVATION



## People living in poverty and deprivation may have less access to palliative care

Research on how people living in poverty and deprivation access palliative care is limited. However, an international systematic review showed that people living in the most deprived areas are less likely to receive palliative care.<sup>[20]</sup> Those in a lower socio-economic position are more likely to experience hospital death and other issues associated with inadequate access to, or lack of, palliative or end of life care.<sup>[21]</sup>

## People living in poverty and deprivation have particular palliative care needs

There is evidence that deprivation impacts on many aspects of the symptoms experienced by people with end of life and palliative care needs. Pain, breathlessness, psychological and spiritual well-being are negatively impacted when people live in deprivation.<sup>[22]</sup> In addition, financial pain has been identified as one of the key issues that affects people who need palliative care. In addition, family carer living in poverty are more likely to experience moderate to severe depression.<sup>[23]</sup> People living in poverty and deprivation have particular palliative care needs that require addressing to improve quality of life.



PHOTO: Palliative care in Bangladesh: WHPCA/BSMMU

## Evidence is limited on the barriers to access to palliative care for people living in poverty and deprivation

While there is limited evidence on why people living in poverty and deprivation have less access to palliative care, there are a number of reasons cited. These include “availability, affordability, acceptability and geographical accessibility of palliative care”.<sup>[24]</sup> It is also suggested that palliative care providers may require more resources in order to provide care to people who are living in poverty and living with palliative care needs.

## Research is extremely limited on the experience of people with palliative care needs living in poverty and deprivation

Evidence shows that there is limited research on how to address the equity issues regarding palliative care for people living with poverty and deprivation.<sup>[25]</sup> The lack of research from and involving the perspective of people who are themselves directly affected is particularly problematic.<sup>[26]</sup>

### Case study: Supporting carers in household facing economic challenges, London, UK

“In 2020, St Christopher’s Hospice in London, UK created a guide for hospice and palliative care staff aimed at supporting carers with no recourse to public funds who are supporting loved ones at the end of their life. It identifies welfare benefits people may not be able to access, the different barriers they may face along the way and affords new partnership working between people who are expert around end of life and those who feel confident working with people with no recourse to public funds.”<sup>[27]</sup>



PHOTO: Palliative care in Bangladesh: WHPCA/BSMMU

Pain, breathlessness, psychological and spiritual well-being are negatively impacted when people live in deprivation.

# PEOPLE LIVING IN HUMANITARIAN EMERGENCIES



## People living in humanitarian emergencies are less likely to access the palliative care they need

Sadly, palliative care is rarely available in humanitarian emergency situations. A systematic review of the inclusion of palliative care in humanitarian emergency guidance found only one reference to palliative care and pain treatment.<sup>[28]</sup> Studies in humanitarian emergency settings including Cox's Bazar in Bangladesh<sup>[29]</sup> and in Gaza<sup>[30]</sup> have found that palliative care is not available to those who need it. The result of lack of access to palliative care for people in humanitarian emergencies is avoidable pain and suffering.

## People living in humanitarian emergencies have particular palliative care needs

While there has been limited research on the palliative care needs of people in humanitarian situations, this is beginning to change. Research conducted in Cox's Bazar Bangladesh found that many people were living with serious pain and suffering that was not being alleviated due to the lack of palliative care services. This included physical, psychological, social and spiritual issues. The study found that 62% of any individuals with serious health problems experienced significant pain, and that the pain treatments prescribed were largely ineffective and effective pain treatments were rarely available.<sup>[31]</sup>

## Much work is being done to improve equitable access to people living in humanitarian emergencies

At all levels, people are working to address the inequitable access to palliative care for people living in humanitarian emergencies. Initiatives including the publication of the World Health Organisation's guide on Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises<sup>[32]</sup>, the advocacy of PalCHASE and the work on the ground providing palliative care in humanitarian situations from Cox's Bazar, Bangladesh to Gaza are all focussed on reducing palliative care inequity.

### Case study

PALCHASE (Palliative care in humanitarian aid situations and emergencies) is a network that was founded to work in partnership through a visible and effective network to advocate for palliative care integration in humanitarian situations or emergencies, to support the development of standards and policies, and a high-quality evidence base, to ensure the full participation and engagement of affected communities and individuals and to enable opportunities for training.

Palchase have succeeded in getting palliative care integrated in SPHERE guidelines and built new partnerships to integrate palliative care into the humanitarian response.<sup>[33]</sup>



# PEOPLE EXPERIENCING HOMELESSNESS



## People who are experiencing homeless are less able to access the palliative care that they need

Evidence shows that people experiencing homelessness have less access to palliative care services than those who are housed.<sup>[34]</sup> <sup>[35]</sup>

## People who are experiencing homelessness have particular palliative care needs

Research has shown that people experiencing homelessness have particular palliative care needs that are often not being met.<sup>[36]</sup> The critical importance of a person centred approach which recognises where people want to receive care and supports people in their choices is crucial. Research also highlights that there is a particular challenge with identifying when people experiencing homelessness are approaching the end of their life. People working in the field highlight the critical importance of putting the patient first, understanding the whole person including past, present and future care, taking a team work approach and exploring existing and potential support structures.<sup>[37]</sup>

## Palliative care programmes globally are trailblazing new initiatives to provide equitable palliative care for people experiencing homelessness

Across the world, palliative care providers are seeking to reduce inequities in access to palliative care for people experiencing homeless. From PEACH in Canada to St Luke's Combined Hospices in Canada, the status quo is being challenged and the inequities in access to palliative care are being addressed.

### Case study

PEACH is a supportive palliative service fostered by Inner City Health Associates (ICHA) in Canada. Aimed to meet the needs of homeless and vulnerably-housed patients with life-limiting illnesses, PEACH's focus lies with the pain, symptoms and psychosocial goals related to each and every patient's life's end. PEACH operates as a "trailblazing" mobile unit, providing attentive care on the streets, in shelters, and with community-based service in collaboration with Toronto Central CCAC (Community Care Access Centre).

**ICHA** | Inner City Health Associates

# PEOPLE WITH DISABILITIES



## People with disabilities are less likely to access the palliative care they need

People with intellectual and physical disabilities are less likely to access the palliative care they need than those without disabilities.<sup>[38]</sup>

## People with disabilities have particular palliative care needs

Evidence demonstrates that people with disabilities have particular palliative care needs. A systematic review of evidence of people with palliative care needs and intellectual disabilities found particular needs in relation to pain management, communication, information and psychological and spiritual support. This included issues such as non-accessible information, challenges with aging carers and lack of expertise on end of life care in the place of care.<sup>[39]</sup> Research has also shown particular needs of people with physical disabilities including accessing care and communication.<sup>[40], [41]</sup> The vast majority of published evidence on palliative care and disabilities is from high income countries and it recognises more could be done to include people with disabilities in the research.

PHOTO: Palliative care in Bangladesh: WHPCA/BSMMU

## There are innovative programmes ensuring disability inclusive palliative care

Innovative programmes are taking place to ensure disability inclusive palliative care. This includes a project in Uganda where the Palliative Care Association of Uganda is linking with the deaf community to ensure that they are receiving the palliative care they need.<sup>[42]</sup> In India, Pallium India produced a white paper on the inclusion of people with disabilities in palliative care.<sup>[43]</sup> Despite this innovative work, evidence on what works to improve equitable palliative care for people with disabilities is limited.<sup>[44]</sup>

80% of people living with palliative care needs in the project are living with disabilities.

### Case study: Piloting a disability inclusive palliative care service in Zimbabwe

In 2020, Island Hospice and Bereavement Service UK and Island Hospice and Healthcare, Zimbabwe accessed UK government funding to pilot a disability inclusive palliative care service in Mutare, Zimbabwe.

The project utilises the Washington Group questions in order to assess the links between people with disabilities and those with palliative care needs and to ensure disability-inclusive services. Data is disaggregated by disability, gender and age and 80% of people living with palliative care needs in the project are living with disabilities. The provision of palliative care is improving quality of life.

The training and continued awareness raising on disability rights and inclusion have been effective to the extent of changing cultural behaviours towards people with disabilities and palliative care needs. Awareness raising campaigns including outreach clinics, radio presentations and direct interaction and education by community based carers at community level played a pivotal role in dissolving issues of stigma and discrimination towards people with chronic illnesses and disabilities. The approaches have seen family members changing attitudes as well as assisting in raising awareness on palliative care and disability advocacy.



PHOTO: Piloting a disability inclusive project in Zimbabwe: Island Hospice and Healthcare funded by the UK government

# LGBTQ+ PEOPLE



PHOTO: Carer Help, Australia

## **LGBTQ+ people are less likely to get the palliative care that they need**

It is widely recognised that LGBTQ+ people are less likely to receive the palliative care that they need.<sup>[45],[46]</sup>

## **LGBTQ+ people have particular palliative care needs**

A number of reports have shown the particular needs of LGBTQ+ people in relation to palliative care and serious illness. In the UK, the national charity Marie Curie, released a report in 2016 entitled “Hiding who I am”.<sup>[47]</sup> The report highlighted some of the specific needs of LGBTQ+ people including anticipatory discrimination, lack of support or recognition of family and lack of support in bereavement phases. The report also highlighted the potential complexity of religion and spirituality in how LGBTQ+ people were cared for.

Barriers to the provision of equitable care for LGBTQ + people include discrimination, criminalisation, persecution, fear, distress, social isolation, disenfranchised grief, bereavement, tacit acknowledgment, homophobia and mistrust of healthcare providers.<sup>[48]</sup> In addition, there is evidence of lack of consideration of the legal components of advanced care planning and end of life care.

## There are numerous guides and recommendations to ensure LGBTQ+ inclusive palliative care

There is increasing programmatic work and evidence on ensuring LGBTQ+ inclusive palliative care for those who need it. These include recommendations on inclusive palliative care during the COVID-19 pandemic<sup>[49]</sup> and a practical guide on transforming professional palliative care practice.<sup>[50]</sup> However, there is little programmatic guidance or documented work on inclusive palliative care for LGBTQ+ people in many low and middle income countries.

### Case study: Pallium India: Working towards LGBTQ+ inclusive palliative care

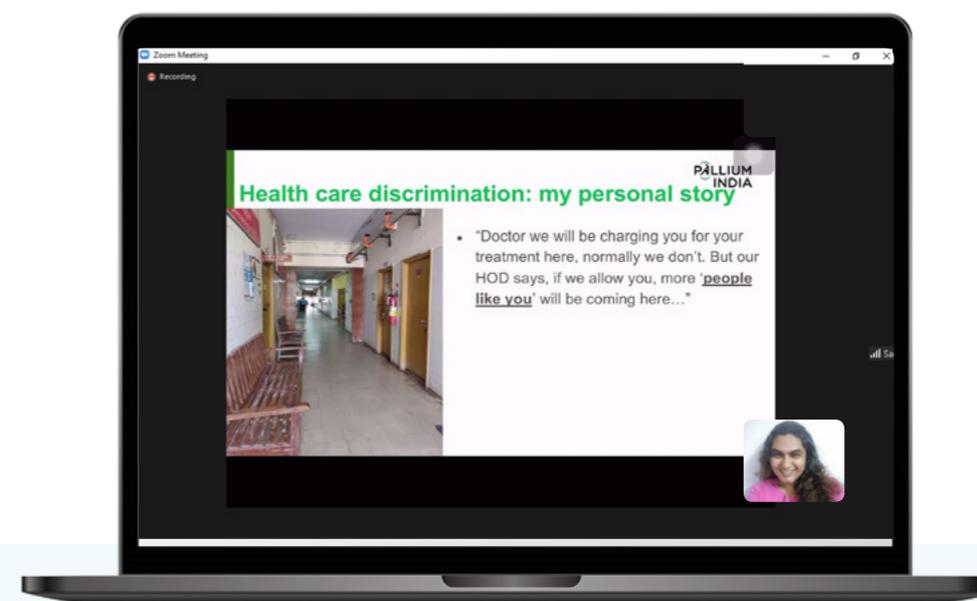
The LGBTQIA movement in India has slowly gained momentum and visibility. Rights-based advocacy in the context of health, legal and social services for communities marginalised on account of HIV status, gender and/or sexuality has been gaining ground. However, access to healthcare and palliative care still remains woefully inadequate.

We recognise the need for platforms through which people who are not directly involved with the issues, or have minimal access to information about these issues are familiarised with them. We also respect the fact that rather than speak on behalf of the community, the community itself should be given the platform to convey the messages.

We included a module in our Foundation Course for Palliative Care, which is aimed at allied and non-medical health workers that is specifically geared to shed light on the challenges faced by the community. We have completed 3 batches, and the 4th is currently underway. Each batch had between 30-50 participants.

#### The module was co-created with members from the community, and covers the following aspects:

- ➔ What do each of the alphabets represent and why it is important to promote inclusivity
- ➔ Understanding gender and sexuality
- ➔ Discrimination amongst the community in healthcare
- ➔ Health Disparities and Legal Issues



- ➔ Special needs of the transgender population
- ➔ LGBTQIA+ and mental health

#### The learning outcomes were:

- ➔ Understanding the needs of the community and being familiar with the terms used to identify themselves
- ➔ Barriers to access to healthcare in general and palliative care in particular
- ➔ What palliative care providers need to do to be more inclusive and sensitive to the needs of the community and provide effective care
- ➔ Identify the increased risks faced in the community
- ➔ Create an inclusive environment · How to communicate with the members of the community; understanding how words and speech patterns have an impact on mental health.
- ➔ Reflecting on our own attitudes in providing healthcare and palliative care to these communities

The feedback from participants demonstrated the value of this module. Several people stated that they had so far been completely removed from and oblivious to these challenges and issues, and pledged to incorporate the learnings in their own practice. The module was delivered by Dr. Sameera Jahagirdar, who is a transwoman and works as a critical care doctor.

(Case study courtesy of Smriti Rana at Pallium India)

# PEOPLE WHO ARE INCARCERATED



## People who are incarcerated have inequitable access to palliative care

People who are incarcerated in many parts of the world do not have access to the palliative care they need. Prison populations in many countries are rapidly aging; by 2030, older prisoners, many of whom have palliative care needs, are expected to account for one-third of the incarcerated population in the US. Incarceration shortens life expectancy and hastens physiological aging, compounding existing health issues and heightening the risk that prisoners will develop palliative care needs.<sup>[51]</sup> For many people with serious illness in prisons, palliative care is not available.

## People who are incarcerated have particular palliative care needs

There are particular palliative care needs for people who are incarcerated and these are context specific. Research from the US and Canada discusses the challenges for people to access information without internet access as well as lack of family support and contact.<sup>[52]</sup> Reports from South Africa talk of prison inmates supporting each other with pain relief at the end of life, with little access to support.<sup>[53]</sup>

## There are projects that are working to address inequities for people who are incarcerated

Projects such as the Humane Prison Project in the US and Hospice Palliative Care Association of South Africa are addressing inequitable access to palliative care in their settings.<sup>[54]</sup> In addition, work has been done to provide guiding frameworks on the delivery of palliative care in prison settings.<sup>[55]</sup>

## Case study

The Humane Hospice Project aims to implement end of life care in prisons by supporting and training prisoners to be the caregivers.

**“When speaking on end of life care, no one should be excluded. Dying with dignity is an essential component of our humanity, and needs to be extended even into the shadows of our society where far too often there are those who will die alone.”**

Marvin Mutch, Humane Program Associate, Social Justice Advocate, formerly Incarcerated prison hospice volunteer and BrothersKeeper co-founder. Recently released via The University of Southern California’s Post Conviction Justice Project after serving 41 years for a wrongful conviction suffered in 1975.<sup>[56]</sup>



# CONCLUSION

There are serious inequities in access to palliative care both across and within countries which have been highlighted in this report. People in low and middle income countries are less likely to get palliative care than those in high income countries. People who are part of marginalised or neglected groups are less likely to receive palliative care than those who are not. This means that people are experiencing avoidable suffering. The existence of those inequities are often well-documented.

There are many examples of organisations and individuals working to address those inequities in their own practice, setting or country. Each providing leadership and undertaking innovative practice to work towards more equitable access to palliative care for all.

Yet, there is more than could be done to understand and learn about what works in relation to addressing palliative care inequities. In addition, the lived experience of people in relation to palliative care inequities is also rarely heard either in the research or in programmatic work. This is a gap.

This report calls for all to reaffirm their commitment to palliative care availability to all who need it: wherever you are born, whoever you love, whatever your age or your background.



PHOTO: <https://unsplash.com>

# ENDNOTES

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