IFMSA Policy Proposal
Palliative and End-of-Life Care

Proposed by SfGH U.K. and MSAI India
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SfGH U.K.

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Policy Statement

Introduction:

The global burden of pain and suffering associated with life-threatening and life-limiting conditions is huge. Evidence suggests this burden could in large part be alleviated by the delivery of high-quality, holistic palliative and end-of-life care. Yet, across much of the globe these services are unavailable throughout the life cycle, a reality that has been described as a crisis in Global Health. Barriers to access include a lack of infrastructure for the delivery of services, difficulties in accessing essential medicines, and the narrow focus in modern medicine on cure and extending life. Actions to increase effective, affordable and contextually-appropriate palliative and end-of-life care are a moral, health and ethical imperative at this time. Fortunately, there are many key areas where IFMSA can advocate for change.

IFMSA position:

IFMSA, as an organisation dedicated to advocating for health equity, highlights the urgent need to ensure that the delivery of high-quality and accessible palliative and end-of-life care becomes an on-the-ground reality for all those who need it. We advocate as a matter of priority for policies and actions that: integrate palliative and end-of-life care into the structure of health systems at all levels of care; strengthen and expand human resources in the field; ensure the availability of essential medicines for palliative and end-of-life services; and support the development of an accountability framework to assess progress. We hold that a commitment to the development of palliative and end-of-life care is a commitment to the achievement of universal health coverage, and of the third sustainable development goal: health and well-being for all – over the entirety of the life course.

Calls to Action:

IFMSA calls on:

1. Governments to:
   a. Develop and implement frameworks and policies for palliative and end-of-life care that are locally and culturally-appropriate;
   b. Mobilise resources – technical, structural and/or financial – to support the inclusive and integrated provision of such palliative and end-of-life care services across all levels of healthcare;
   c. Ensure an increase – proportional to local needs – in a trained and effective workforce in palliative and end-of-life care, through training in these fields both for specialists and relevant non-specialists;
   d. Adopt medicines policies that guarantee the affordable availability of essential medicines for palliative and end-of-life care;
   e. Guarantee that services are economically accessible to those who require them;
   f. Strengthen national and multinational capacities for research in these fields;
   g. Use a multisectoral approach to these aims that includes partnerships between government and non-governmental actors, such as service providers, academics, as well as patients and their caregivers;
   h. Put in place monitoring and evaluation frameworks for the measurement of progress in the development of palliative and end-of-life care.

2. Hospitals and healthcare providers to:
   a. Ensure equitable access to palliative and end-of-life care medicines and services by patients in need, to support them in reaching the highest attainable quality of life;
   b. Integrate holistic palliative and end-of-life care into primary healthcare, community and home-based care, as well as general hospital and specialist services;
   c. Facilitate effective continuity of care between different levels of healthcare and different service providers;
d. Train healthcare providers with the knowledge and skills to provide person-centred palliative and end-of-life care services, including the appropriate administration of medications such as opioids for pain relief;

e. Support care providers such as family and community members in addressing the psychological, emotional, social, existential and spiritual needs of patients;

f. Advocate within the healthcare community for greater openness about, and a conscious orientation towards, the relief of pain and suffering, including near the end of life.

3. Health training institutes to:
   a. Include mandatory clinical and theoretical palliative and end-of-life care education in the curricula of healthcare programmes (e.g., medical and nursing school);
   b. Train healthcare students according to the needs of the local palliative and end-of-life care patient populations;
   c. Recognise intersectoral collaboration as essential to palliative and end-of-life care, and hence promote and engage in intersectoral education and practice of these disciplines.

4. Universities and the global academic community to:
   a. Establish greater capacities for evidence and research programmes in palliative and end-of-life care;
   b. Continue to develop tools for the measurement of palliative and end-of-life care service infrastructure across the globe, and to identify which populations are in greatest need of the holistic provision of these services;
   c. Research and support the development of policies that are appropriate to local contexts and cultures – for example, by conducting more international comparative research on palliative and end-of-life interventions, using culturally and historically informed methods.

5. The World Health Organisation and other technical agencies to:
   a. Create an accountability mechanism tied to the WHA Resolution 67.19 that includes specific indicators, targets, and recommendations for the achievement of universal access to palliative and end-of-life care as part of universal health coverage;
   b. Provide governments with technical advice, resources for research, education and political momentum to form actionable policies on palliative and end-of-life care;
   c. Create more spaces for the global sharing of knowledge and practices among governments to address palliative and end-of-life care within their populations.

6. IFMSA, its NMOs and other student organisations to:
   a. Stimulate open discussion on pain and suffering; life-threatening and life-limiting illness; as well as death and dying, in order to reduce stigma relating to these topics;
   b. Advocate for full access to high-quality palliative and end-of-life care for members of their communities, as well as individuals in need worldwide;
   c. Lead on context-sensitive advocacy campaigns calling for equitable access to medicines necessary for palliative and end-of-life care, including opioids;
   d. Participate in education and research activities on palliative and end-of-life themes, enrolling these activities in the IFMSA programme for Ethics and Human Rights in Health;
   e. Identify organisations that are already working on these issues and consider collaboration.

7. Civil society to:
   a. Engage openly and constructively in conversations about pain and suffering, incurable illness, as well as death and dying.
Position Paper

Background information:

Whether rich or poor, young or old, living in the Global South or North, death is the common condition that will, in time, affect all of those who live. Palliative and end-of-life care are together a relatively new discipline, borne out of this knowledge and the need to integrate the care of those with life-threatening and life-limiting illnesses, as well as of those approaching death, into the heart of medicine. The WHO defines palliative care as a branch of medicine that seeks to improve the quality of life of patients and their families, as they face the problems associated with life-threatening or life-limiting illness. Central to achieving this aim is the prevention and relief of suffering, through the assessment and management of physical symptoms and pain, as well as a holistic approach to the psychological, emotional, social, existential and spiritual needs of patients. End-of-life care is included within palliative care, but is only one aspect of it. End-of-life care focuses on the treatment, care and support of people who are nearing the end of their life – specifically, for those who are thought to be in their last year of life. This may be because of illness, or as a result of the natural process of aging.

It is striking that the development of palliative and end-of-life care has until recently been an afterthought on the Global Health agenda, despite the substantial need for such services the world over. The result is that 25.5 million of 56.2 million people who died in 2015 experienced serious health-related suffering. Of these 25.5 million, 80% lived in low- and middle-income countries. If current trends continue, it is estimated that by 2060 48 million people each year will die suffering, with the largest proportional rise occurring in low-income countries. Whilst the World Health Assembly in 2014 passed a landmark declaration calling upon all governments to integrate the provision of palliative care into their healthcare plans, more recent research highlights that service provision, supporting policies, education, and funding are incommensurate with rapidly growing needs.

Discussion:

1) What are some of the current barriers to the development of palliative and end-of-life care services globally?

A. Limited existence of, and access to, holistic services

Of 198 countries studied in 2017, only 30 (15%) have advanced integration of palliative and end-of-life care services into healthcare systems, whilst 47 (24%) have no known palliative care activity. Of the remaining 121, 13 are in the capacity-building stage, 65 offer isolated provision, 22 have generalised provision, and 21 are in the process of preliminary integration into mainstream provision. When analysed by location, it is shown that the world population is effectively split down in the middle: countries with the highest levels of palliative care development are concentrated in the Global North, whilst 53.3% of the world’s population live in territories with very limited palliative and end-of-life care development, clustered largely in the Global South. Palliative care service infrastructure is underdeveloped overall and inequitably distributed across the world.

Thus for many, particularly in the Global South, the “access abyss” looks like a lack of service provision. However, even within countries measured as having higher levels of palliative care infrastructure, there remain significant barriers to the equitable access of services. For example, in the United Kingdom, which is considered to have palliative care at an advanced stage of integration, research highlights that still, every year up to 110,000 people who need palliative care die without receiving it. In particular, it is stressed that those with illnesses other than cancer face a lack of access to services.
since having a cancer diagnosis is the primary determinant of access to specialist palliative and end-of-life care\textsuperscript{14}. This is in spite of the fact that there is comparable symptom burden in all types of advanced illness\textsuperscript{14}. Lack of public awareness and a lack of affordable payment models also limit access to services in other countries reported as having a high level of service provision\textsuperscript{8,15,16}.

Finally, the nature of services being accessed also requires attention. As highlighted by qualitative research, the social and existential needs of patients are often better met in locations classed as having fewer palliative care services, relative to their counterparts with services at a more advanced level of integration into healthcare\textsuperscript{17,18}. These findings highlight that nowhere are palliative and end-of-life care provisions ‘perfect’: that needs such as social and existential are not always addressed by existing services is as much a shortcoming as lack of access to resources targeting, for example, physical suffering.

B. Lack of availability of essential medicines for palliative and end-of-life care, particularly opioids

A further well-documented barrier to the delivery of effective palliative and end-of-life services is the difficulty that many countries face in accessing essential medicines for these types of care\textsuperscript{9}. The inequitable distribution of opioids is particularly problematic: 298.5 metric tonnes of morphine-equivalent opioids are distributed around the world every year, of which only 0.1 metric tonne is distributed to low-income countries\textsuperscript{19}. Opioid analgesics are effective and inexpensive drugs, why should it be the case that they are so difficult to access for so many? Research has suggested several explanations. First, that palliative care and end-of-life care have long been neglected in Global Health, and therefore imperatives to increase access to their necessary medicines have failed to translate into improvements in the field. In particular, the lack of existence of priority-setting tools to incorporate suffering into the measurement of health outcomes and to inform investment decisions has been highlighted as limiting progress\textsuperscript{20}.

Second, the role of ‘opiophobia’ is stressed, i.e., the prejudice and misinformation that exists about the medical use of opioids among prescribers, as well as in social and cultural perceptions of opioids\textsuperscript{20,21,22}. The complex history of opioids, the ‘War on Drugs’ and the opioid crisis that continues in the US have understandably served to drive the scarcity of medical opioids elsewhere\textsuperscript{21,22}. Yet there is now much research to show that opioids for palliative and end-of-life care have a low abuse potential when used appropriately, and can have profoundly beneficial effects on relieving pain\textsuperscript{9,21,22,23,24}. Indeed, both oral and injection morphine are on the WHO Model List of Essential Medicines\textsuperscript{20,23}.

Finally, morphine is ‘off-patent’: whilst ‘off-patent’ drugs are in theory less expensive, their small profit margins disincentivise drug companies from producing them\textsuperscript{19}. The lack of a reliable supply means that smaller countries struggle to command a reasonable price for morphine\textsuperscript{9,21}, reflective of its low manufacturing costs. Since many of these nations need only a relatively small number of doses, pharmaceutical companies charge them much more to start up production\textsuperscript{21}. In practice this means that they pay many times the US and UK prices for the same morphine: Rwanda, for example, pays nearly six times the lowest international price for injectable morphine\textsuperscript{9,21}.

C. The biomedical aversion to death

The focus in modern medicine on curing illness and extending life has been proposed as a further barrier to the development of palliative and end-of-life care\textsuperscript{8,26,27}. It is argued that the wider institution of biomedicine regards death as something to be resisted, delayed, or avoided\textsuperscript{1}, leading to a concomitant neglect of caregiving and quality of life for those with irreversible, life-limiting illness or those approaching death\textsuperscript{1,9}. These notions could in part explain why palliative and end-of-life care have remained low on the Global Health agenda\textsuperscript{6}.
2) How might some of these barriers be overcome?

A. Increasing the provision of palliative and end-of-life care services worldwide and for all

There are many actions that can be taken to achieve this goal. First, the evidence base around palliative and end-of-life care should be examined\(^2\), with a view to establishing its current cost-effectiveness; impact on the community and health systems; as well as on outcomes for patients, caregivers and healthcare workers. This includes studying not only the elements relevant to physical suffering, but prioritising an understanding of the interventions that support the psychological, emotional, social, existential and spiritual needs of patients. The missing gaps in the evidence base should be identified, and a research agenda developed and funded into order to address these shortfalls\(^2\). The populations of low- and middle-income countries continue to be the most affected by serious health-related suffering\(^9,10\), yet most palliative and end-of-life care research to date has focused on high-income countries\(^9\). Research in low- and middle-income countries to establish their national needs, and the interventions that are likely to be most suitable and effective at meeting them, should be an absolute priority on the research agenda\(^9\).

Second, national governments should develop and implement budgeted action plans to scale up access to affordable and holistic palliative and end-of-life care services for all those in need. These services will need to be appropriately integrated into existing health and community-based support systems\(^2\). People living with life-limiting conditions, as well as those approaching death through old age, their carers and health professionals should be consulted in the development of any policies and services addressing palliative and end-of-life care. Governments should monitor progress in the development of infrastructure, and be able to produce evidence of implementing equitable and sustainable improvements, which address all of the aforementioned needs. To support these objectives, greater integration of context-relevant palliative and end-of-life care education and training into the local undergraduate and postgraduate curricula of medicine, nursing and other relevant disciplines should be ensured\(^9,28\), and appropriate training of non-specialist caregivers facilitated\(^9,28\).

Third, the WHO and other technical agencies\(^9\) should provide guidance and support for policy makers in national governments on how to create holistic infrastructure for palliative and end-of-life care. This guidance should include strategies for the integration of services into existing healthcare systems across disease groups and levels of care. Technical agencies are also likely to have the capacity to build political momentum around investment – of money, time and collective energy – into the development of palliative and end-of-life care, an ability that they should levy.

Finally, there must also be an accountability framework that supports the coordination and delivery of actions, in response to policy commitments\(^9,28\). The WHO and WPCA have suggested that a global task force could be set up, supporting scale-up through the provision of specific targets, and using measurable benchmarks to hold individual stakeholders accountable to improvement\(^28\). IFMSA endorses the creation of such a task force.

B. Ensuring access to opioids and other necessary medicines for palliative and end-of-life care

The Lancet Commission on Palliative Care and Pain Relief created an affordable “essential package”\(^9\) of palliative care, including an evidence-based list of 20 medications that should be available in any health system, no matter how resource-constrained\(^5\). Both immediate-release oral and injectable morphine are key to this list\(^9\). The essential package is one of the least costly of the components that form the DCP3 Essential Universal Health Coverage Package\(^30\); taken together, all the recommendations are estimated to cost low-income countries 2.16 dollars per capita per year (2-3% of

\(^{2}\)For example, the Global Fund to ensure the inclusion of palliative and end-of-life care within their proposals; UNICEF to take a leading role in promoting the development of these services for children in need; INCB in reinforcing efforts to guarantee countries adequate and affordable availability of essential medicines for palliative and end-of-life care.
the cost of the essential UHC package). Costs could be further reduced by securing access to best international prices for medicines, including morphine. It is estimated that this would decrease the price of the essential package for low-income countries by about 25%9. Achieving this reduction will likely require collection action at local, national and international levels to advocate for global access to lowest prices. IFMSA is well-placed to take a leading role in such advocacy.

Further, in order to increase the acceptability of the use of opioids, and hence likely uptake of the essential package, efforts to sensitively address ‘opiophobia’ will be necessary31. Locally, increased training for healthcare workers on how to safely use opioid medications should be reliably provided. Nationally and internationally, advocacy and awareness-raising of the evidence-base on using opioids in palliative and end-of-life care would likely be of benefit, though these should be conscious of the painful history of opioids that has created resistance to them in the first instance9,31,32. There is already evidence of the success of such campaigns, in supporting the increased consumption of morphine and the development of palliative care services in countries such as Uganda31,33. Again, IFMSA could support relevant advocacy campaigns, in an informed and contextually-sensitive manner.

In addition to the essential package and supportive activism, adequate access to opioids and other necessary medicines will require increased investment in comprehensive palliative and end-of-life care service infrastructure, – as detailed in section 2A – as a platform from which appropriate medication delivery can occur6,17.

C. Making sure that services developed are culturally and locally appropriate

A framework for prioritising the development of palliative and end-of-life care service infrastructure and ensuring access to necessary medicines has been laid out in sections 2A and 2B. It is worth considering how the precise interventions offered may vary across settings. Different concerns and practices around incurable illness, death and dying reveal themselves in different contexts34. For example, a systematic review of palliative care in Sub-Saharan Africa has shown that it is principally provided at home35. Joardar has described how some Bangladeshi people highly value a dying process and death where the patient is in the presence of loved ones36. Here, the collective or relational self plays a more prominent role in individual life and ethical behaviour than the more Western notion of autonomy34,36. Further, Stonington recounts the different ethical locations that are important for patients with incurable illness in Buddhist Northern Thailand, detailing how both the hospital and home are involved in achieving “a good death”37.

In this light, the uncritical transfer of practices from one context to others seems unwise34. A helpful aim might be the translation of practices hoping to achieve broadly similar goals, – the appropriate alleviation of pain and all forms of suffering – but in ways that are tailored to particular contextual needs. The concept of “value-logistics34,35” might prove useful here: where value refers to one’s judgment about priorities for incurable illness and the end of life, and in turn logistics denotes the arrangements (including medical services) needed to achieve the stated value34. In practice this means that in the current palliative care and end-of-life narrative of much of the Global North, the value might include significant medical intervention, followed by a dignified, pain-free and controlled death34,38,39. Hence, the logistics needed are hospitals, the availability of medications and technology, as well as hospice services34. In alternative narratives of value, high quality care might be best achieved through community-based palliative and end-of-life services provided by teams of specialists and non-specialists, with loved ones integrated into the delivery of care34,40. The success of such a model has already been shown by The Neighbourhood Networks in Palliative Care in Kerala, India, where a sustainable, community-led service is capable of providing palliative and end-of-life care to all those in need, even with limited resources34,41. In still other locations, high quality care might require the availability of both hospital-based and community-centred strategies34,35.

Overall, in specifying the nature of palliative and end-of-life care services, care needs to be taken not to privilege one particular future globally, but to seek a suite of solutions. It is critical to consider all the components that may be relevant, – physical, psychological, emotional, social, existential and spiritual – and to identify common denominators of palliative and end-of-life care needs around the world, whilst also conceptualising where contextual requirements differ, for example by using the value-logistics tool.
From there, efforts can focus on developing culturally and locally appropriate services that are accessible, and that will not inflict financial hardship on those who need them.\textsuperscript{42,43}

**Conclusion**

Palliative and end-of-life care are key to the achievement of universal health coverage, and should be seen as an urgent Global Health priority. Concerted actions are needed at local, national and international levels in order to turn previous policy commitments into a reality of increased and improved holistic palliative and end-of-life care infrastructure on the ground, accessible to all those who would benefit from it. Changes implemented should be multidisciplinary, humanistic, and culturally-sensitive, in order to appropriately support the alleviation of human pain and suffering in its many guises, in the many locations in which it occurs.

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