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. 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 key areas where SfGH can advocate for change.

SfGH position:

SfGH recognises the global burden of pain and suffering associated with life-threatening and life-limiting conditions, and the need for services to support its equitable alleviation worldwide. We support the World Health Assembly resolution WHA67.19, and support policies 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 recognise that a commitment to the provision 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:

1. SfGH should:
   a. Affirm and advocate for equitable access to high-quality palliative and end-of-life care as a pillar of universal health coverage;
   b. Stimulate open discussion on the relief of pain and suffering; life-threatening and life-limiting illness; as well as death and dying, in order to reduce stigma relating to these issues, and increase awareness of the need for appropriate care;
   c. Raise awareness about and deliver education on palliative and end-of-life care, and barriers to these services, for example, by running training sessions, educational events, and talks at national events such as conferences;
   d. Lead on advocacy campaigns calling for equitable access to medicines necessary for palliative and end-of-life care, particularly opioids;
   e. Identify organisations that are already advocating on these issues and consider collaboration.

2. Branches and members should:
   a. Advocate for full access to high-quality palliative and end-of-life care for members of their community and individuals in need worldwide;
   b. Participate in education, research and advocacy activities on palliative and end-of-life issues;
   c. Ensure their institutions include palliative and end-of-life care teaching as part of the core curriculum of relevant subjects (including, but not limited to, medicine and nursing);
d. Encourage their institutions to invest in, and provide more opportunities for, multi-disciplinary research into palliative and end-of-life care.

3. Governments, including in the United Kingdom (UK), should:
   a. Develop 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 palliative and end-of-life care services are economically accessible to those who require them;
   f. Strengthen national and multinational capacities for research in palliative and end-of-life care;
   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 evaluation and accountability frameworks for the measurement of progress in the development of palliative and end-of-life care.

Background:

Palliative and end-of-life care are a relatively new discipline, borne out of the need to integrate the care of those with life-threatening and life-limiting illnesses into the heart of medicine. The World Health Organisation 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 thought to be in their last year of life. This may be because of illness, or the natural process of aging.

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. 80% of these people lived in low- and middle-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 health plans, 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 services, and difficulties in accessing them where they do exist

Of 198 countries\(^1\) studied in 2017\(^8\), 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\(^8\). When analysed by location, it is shown that the world population is effectively split down in the middle\(^5\): 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\(^6\). Palliative care service infrastructure is underdeveloped overall and inequitably distributed across the world\(^8\).\(^9\).\(^10\).

For many, particularly in the Global South, the “access abyss”\(^10\) 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. In the UK, which is considered to have palliative care at an advanced stage of integration\(^9\), research suggests that every year up to 110,000 people who need palliative care die without receiving it\(^13\). In 2014, only 21% of hospitals offered face-to-face access to specialist palliative care seven days a week despite national recommendations, and only 2% of hospitals provided 24-hour access\(^13\). Further, those with illnesses other than cancer face a lack of access to services in the UK\(^14\), since having a cancer diagnosis is the primary determinant of access to specialist palliative and end-of-life care\(^14\). This is in spite of the fact that there is comparable symptom burden in all types of advanced illness\(^14\). Lack of public awareness and a lack of affordable payment models also limit access to services in other countries recorded to have a high level of service provision\(^15\).\(^16\).

Finally, the nature of services being accessed also requires attention. As underscored 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\(^42\).\(^43\). 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 physical suffering.

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

A 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\(^5\). 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\(^17\). 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, palliative care and end-of-life care have been long neglected fields in global health; accordingly, increasing access to their necessary medicines has not been a priority, and has largely not occurred. In particular, the lack of existence of priority-setting tools to

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\(^1\)193 member states of the United Nations, two observer states, Kosovo, Somaliland and the state of Taiwan.
incorporate suffering into the measurement of health outcomes and to inform investment decisions has limited progress.\(^8\)

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.\(^8,10,20\). The complex history of opioids, the ‘War on Drugs’ and the opioid crisis that continues in the US have served to drive the scarcity of opioids\(^9,20\). Yet there is 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\(^9,19,20,21,22\). Indeed, both oral and injection morphine are on the WHO Model List of Essential Medicines\(^9,23\).

Finally, morphine is ‘off-patent’: whilst ‘off-patent’ drugs are in theory less expensive, their small profit margins disincentivise drug companies from producing them\(^9\). The lack of a reliable supply means that smaller countries struggle to command a reasonable price for morphine\(^9,19\), 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\(^9\). In practice this means that they pay much more for the same morphine: Rwanda, for example, pays nearly six times the lowest international price for injectable morphine\(^9,19\).

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\(^9,24,25\). It is argued that the wider institution of biomedicine regards death as something to be resisted, delayed, or avoided\(^1\), leading to a concomitant neglect of caregiving and quality of life for those with irreversible, life-limiting illness or those approaching death\(^1,9\). These notions could in part explain why palliative and end-of-life care have remained low on the Global Health agenda\(^6\).

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

First, the evidence base around palliative and end-of-life care should be examined\(^26\), 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\(^26\). The populations of low- and middle-income countries continue to be the most affected by serious health-related suffering\(^8,10\), yet most palliative and end-of-life care research to date has focused on high-income countries\(^27\). Research in low- and middle-income countries to establish their national needs and which interventions are likely to be most effective, should be an absolute priority on the research agenda\(^27\).

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\(^26\). People living with life-limiting conditions, 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 on the development of infrastructure, and be able to produce evidence of implementing equitable and sustainable improvements. To support these objectives,
greater integration of context-relevant palliative and end-of-life care education and training into local undergraduate and postgraduate curricula of medicine, nursing and other relevant disciplines should be ensured\(^{15,26}\), and appropriate training of non-specialist caregivers facilitated\(^{15,26}\). SfGH can contribute to education on palliative and end-of-life care by incorporating related talks, conferences and other educational events into the organisation’s programme.

Third, the WHO and other technical agencies\(^{2}\) should provide guidance and support for policy makers in national governments on how to create 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\(^{2,5,26}\). 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\(^{26}\). SfGH 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\(^{8}\). Both immediate-release oral and injectable morphine are key to this list\(^{8}\). The essential package is one of the least costly of the components that form the DCP3 Essential Universal Health Coverage Package\(^{28}\): taken together, all the recommendations are estimated to cost low-income countries 2.16 dollars per capita per year (2-3% of the cost of the essential UHC package)\(^{9}\). Costs could be reduced further by securing access to best international prices for medicines, including morphine. It is estimated that this would reduce the price of the essential package for low-income countries by about 25%\(^{9}\). Achieving this will likely require collection action at local, national and international levels to advocate for global access to lowest prices. SfGH is well-placed to generate awareness, and contribute to such advocacy.

Further, in order to increase the acceptability of the use of opioids, and hence likely uptake of the essential package, efforts to address opiophobia will be necessary\(^{19}\). 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\(^{9,29,30}\). 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 Uganda\(^{29,31}\). Again, SfGH could support relevant advocacy campaigns.

In addition to the essential package and supportive activism, adequate access to opioids and other necessary medicines will require increased investment in palliative and end-of-life care service infrastructure, – as detailed in section 2A – as a platform from which medication delivery can occur\(^{6,7}\).

\(^{2}\)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.
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 contexts. For example, a systematic review of palliative care in Sub-Saharan Africa has shown that it is principally provided at home. Joardar has described how Bangladeshi people highly value a dying process and death where the patient is in the presence of loved ones. Here, the collective or relational self plays a more prominent role in individual life and ethical behaviour than the more Western notion of autonomy. Finally, Stonington describes the different ethical locations that are important for patients with incurable illness in Buddhist Northern Thailand, recounting how both the hospital and home are involved in achieving “a good death.”

In this light, the uncritical transfer of practices from one context to others seems unwise. A helpful aim might be translation of practices hoping to achieve broadly similar goals, – the appropriate alleviation of pain and suffering – but in ways that are tailored to particular contextual needs. The concept of “value-logistics” 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 value. In practice, this means that in the current palliative care and end-of-life narrative of much of the Global North, including the UK, the value might include significant medical intervention, followed by a dignified, pain-free and controlled death. Hence, the logistics needed are hospitals, the availability of medications and technology, as well as hospice services. 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 care. 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 resources. In still other locations, high quality care might require the availability of both hospital-based and community-centred strategies.

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.

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 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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