African Palliative Care Association Conference 2022

Narrative for plenary presentation

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Advocacy for Controlled Medicines in Health Systems

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1. I'd like to start by thanking the APCA organizers and saying what a great honor it is to give a plenary at the Conference. I have been listening remotely for the past few days and am blown away by the brilliant presentations and progress being made across the continent. The work in Uganda, originated by Dr Anne, has inspired my advocacy from Day One and I wish I were with you in person to go out with the home care teams. IAHPCs travel budget is not what it used to be and we would rather use our scarce funds to pay for our scholars who are here in person. Today I will talk about how and WHY IAHPC advocates for improving access to controlled medicines. Many of you who have taken my course will recognize some of the points I make. Anyone who is a member can take the courses and learn the details of what I will go through quickly today.
2. Organizing: I will introduce the IAHPC, talk us through some key definitions so we are all on the same page, paying particular attention to the concept of equity, and cite some of the authorities that support our advocacy for controlled medicines. What I hope you take away from this talk is a clearer understanding of why advocacy for controlled medicines is both so difficult and so critical. Advocacy not only supports providers, it supports policymakers who need to show that their countries are complying with international human rights obligations and making progress towards the 2030 Agenda for Sustainable Development, or SDGs. Palliative care integration can tick a lot boxes on a lot of different agendas, but it must be better known. Advocacy brings palliative care practice into the halls of government and public affairs.
3. IAHPC is a global non-profit membership organization whose vision is a world free from health related suffering. We are officially accredited by the United Nations to participate in meetings of its agencies. That is where we advocate for improved access to essential medicines and have made much progress in the authorizing framework for all practitioners everywhere. IAHPC is represented in person at this conference by board Eve Namisango, Dr Nahla Gaferfrom Sudan and Mary Callaway from the US. Also from the US is Cristina Montanez and traveling scholars Rose Gahire from Kigali, Coumba Gueye from Dakar, Cris Mindiera from Lolongwe, Tonny Mwabury from Losotho, Tonya Onyeka from Nigeria, Esther Taaka from Uganda, a home girl. There are many IAHPC members at this conference, and we hope many more will sign up! As Senior Advocacy and Partnerships Director, I work to raise the profile of palliative care in global health policy, and to improve understanding at all levels about the value of ensuring adequate access to internationally controlled essential medicines such as the oral morphine Hospice Uganda makes at its own lab.
4. I am going. to give a few basic definitions so we are all on the same page. Advocacy for controlled medicines needs to be clear and consistent since these substances are muffled in so much myth from the past. Many of you know these definitions, so you will get a refresher. We will start by defining Advocacy, which is not as mystifying as some people belief.
5. Advocacy is when individuals or groups educate policymakers to bring about change on behalf of a particular health goal or population. We do this by building partnerships to reach the advocacy goal of a world free from health related suffering. A more colloquial definition would be that we sing palliative care medicine's praises at international meetings and talk about how, properly used, they reduces suffering. Suffering now has a metric. It has been measured. Current global health priorities are reducing mortality and extending life expectancy. These goals must be supplemented with practices that relieve suffering in the context of reduced mortality and extended life expectancy since 100% of us still die. This is a population level issue, and therefore a concern of member states and therefore a topic of advocacy. .

6. The definition of internationally controlled essential medicines has two parts internationally controlled AND essential, which correspond to two different UN Agencies, one of which controls “drugs” the other is responsible for public health. We try to avoid using the term drugs, because it is confusing and stigmatizing, yet it is encoded in international law, as you can see on the left. Medicines that are Internationally controlled contain ingredients listed in the schedules attached to the international drug control conventions, which were approved in the middle of the last century, three generations ago and still overseen by the Commission on Narcotic Drugs in Vienna. Essential means they are ALSO included in the WHO Model List, a list that IAHPC contributed to, and which now contains a separate Part 2, on palliative care medicines. Now we have some UN declarations saying they must be available in a pandemic. The important thing to remember is that governments are the gatekeepers and that they must all ensure BOTH that these essential medicines are available AND that diversion and harmful non-medical use are kept to a minimum. This is the principle of balance.
7. The principle of balance ensures adequate availability internationally controlled essential medicines while preventing diversion and harmful non-medical use. Most regulatory systems today are UNbalanced, not allowing sufficient access to controlled medicines and failing to prevent harmful non-medical use. Balance is also connected to justice, or proportionality. It is a matter of global health justice, that interantionally controlled essential medicines are equitably distrbuted both within and between countries to alleviate what in the 21st century is entirely preventable suffering. All African governments, and the African Union have recognised the need to improve access through balanced policies. This recognition is the result of advocacy for service provision and access to medicines and brings us to the concept of EQUITY, which is also connected with justice.
8. You are all familliar with this map showing Inequity or imbalance , I think from the Lancet Commission on Pallaitive Care and Pain Relief, published in 2018. It shows in graphic form the inequity in access to interantionally controlled essential medicines for the relief of suffering measured in distributed opoid morphine equivalent, which just means the amount of morphine distributed throughout the world according to estimated need, since the WHO approves morphine consumption as an indicator. The map considers Western Europe the standard, showing the rest of the world in relationship to that measure. It is important to note that there is no opioid crisis in Germany, which is the benchmark country, as compared to the US, where according to the map there is an oversupply in relation to need. This is a problem of governance, not the opioid itself, and can be corrected through appropriate regulation and suppy chain strengthening, which can only come about through focused collaborations between civil society and government.
9. Equity, unlike equality, which means everyone gets the same, no matter their starting point, refers to fairness and ustice, and the process of identifying and overcoming intentional and unintentional barriers. IAHPC advocates for equity in access to controlled medicines at the global level. One of the primary barriers, which actually includes many of the sub-barriers, is rooted in the historical context of the Single Convention on Narcotic Drugs, and the fact that many UN member states have not yet integrated 21st century advances in palliative and addiction medicine into their educational and regulatory frameworks. They have laws and regulations on the books that date back to the days of the Single Convention, and have not trained their health workforces to use essential medicines such as opioids, even though the international framework now encourages that. Now I’m going to briefly take you through the timeline that has produced this situation of inequity that requires advocacy, and finish on a positive note, accomplishments.
10. The timeline gives an idea of where we came from and where we can go. It shows that history and advocacy matter. There was more than a century of drug control before there was active and professional advocacy for controlled medicines. Controlled medicines were essentially absent from the drug control agenda between 1910 and 2010. Now availability is central to that global narrative thanks to global advocacy. Uganda and some other African countries are doing so well now thanks to advocacy from APCA and partners for strong regulators and innovative practices such as nurse

prescribing. They are leading the way as models for Low and Middle Income Countries and we cite them as an example at international meetings.

11. I apologise for this busy slide, which I hope shows just how much advocacy has achieved in a very short time against all the odds. For almost a century, three generations – the bottom half of the slide -- this international system has taught governments to suppress demand for and supply of substances containing what are called "narcotic drugs." As we now know, these include essential palliative care medicines. But palliative care and addiction medicine were **non-existent** during that time. Now that both are developed, we advocate for INCREASED demand and supply, with appropriate safeguards to prevent diversion and harmful non- medical use of course. The timeline shows that have been only two only decades of awareness raising about the abyss in access to medicines – advocacy by providers such as those trained by the Pain and Policy Studies Group. Those two decades of evidence based advocacy have expanded the the global drug control narrative and have put improved availability of essential medicines at the center of international drug policy. There are still many challenges though.
12. These are just a few -- we have the 20th century, outdated "drugs" model, which is still very compelling to policymakers and attracts lots of funding, weapons, surveillance material, police training, etc. We should demand equal time and equal funding! And now the US opioid crisis, which is being blamed on prescription medicines, dominates the headlines although the evidence shows that the current opioid crisis is entirely caused by a toxic combination of the socio-economic determinants of health and illegally trafficked fentanyl. The US opioid crisis represents regulatory failure to resist the power of the transnational pharmaceutical industry. We can learn from this failure and correct for future problems through education, balanced regulations, pooled procurement of generics, and supply chain strengthening. Without advocacy to governments, the private sphere alone, not patients, stand to benefit from investment in palliative care. We also challenge narratives that focus exclusively on saving lives and extending mortality, The euthanasia assisted dying movements get stronger every day as long as palliative care remains unavailable. We need funding, advocacy, and new marketing strategies, and I am confident that the talent exists at this conference to make that happen
13. So given what we have just learned, it should be no surprise that the first advocacy response is to promote evidence based palliative care medicine. There are a lot of misunderstandings, including unfortunately, that palliative care is a form of euthanasia, which IAHPC disputes. We also advocate by presenting compelling patient and caregiver stories. Advocacy shows hospitality by inviting policymakers and influencers to see how our services work, and to go on home visits with teams to see the magic of palliative care in action. We develop partnerships and convene all stakeholders to craft sustainable policy in pursuit of the goal of creating a global palliative care movement. This must involve the community as a whole and people of all ages to advocate for themselves and their loved ones, to act as citizens in their own districts, countries and regions.
14. We also mobilized with our partners at the beginning of the pandemic to produce a series of 26 briefing notes and associated webinars on COVID and palliative care, including access to controlled medicines, which triggered some very high level responses from the UN Agencies on ensuring availability. You can find the texts in the sources slide.
15. Finally, our wins, what we have accomplished in just the last decade, in partnership with most of the organizations and many of the people in this room. The No Patient Left Behind initiative was launched as part of the 2022 Call to Action by the Ambassador D'Hoop of Belgium, Chair of the Commission for Narcotic Drugs this year. He is making serious efforts to give visibility to our advocacy. A few recent products have been the two Joint Statements in 2020 and 2021 by the INCB, UNODC and WHO on improving access to controlled medicines, particularly in emergencies. The Astana Declaration on Primary Health Care now includes access to palliative care as part of the spectrum of primary care. The UNGASS Outcome Document from 2016 now includes a whole chapter of programmatic recommendations for governments needing to improve access. For funding to implement the goals your government has supported in all these documents, I suggest

that you advocate for them to apply for the World Bank Funding to strengthen health systems and prepare for future pandemics. That is the subject of much of the work at this conference, and the World Bank has funding for it. You need to advocate with your governments to apply for it.

16. My main takeways are that we should be patient, because we are still relatively new. But we must also be passionate. Advocacy for palliative care medicines is changing the drug control narrative encoded in the Single Convention. Our advocacy needs to be passionate, a word that comes from the Latin *patior,* which means to suffer. It expresses the idea of being moved to action where there is pain and suffering. Our advocacy work for controlled medicines seeks to relieve suffering to the greatest extent possible. That is why IAHPC's vision is a world free from health related suffering and why once again I thank you for being able to share our work at this great conference. Uganda is lighting the way, as this photo of Dr Anne with the incoming class at HAU Institute shows.
17. This is all I have time for today on the importance of advocacy for controlled medicines. I know this has been just a small taste of the work we do at IAHPC to promote palliative care and access to internationally controlled essential medicines. Members can take my advocacy course and have access to the other educational courses at the institute as well as sign up for scholarship applications and research opportunities and mentorship. Thank you again for having me and congratulations on the conference.