

HIGHLIGHTS FROM THE FIELD ON THE IMPACT OF THE PALLIATIVE CARE AND ACCESS TO CONTROLLED MEDICINES ADVOCACY WORKSHOPS HELD DURING THE 5TH AFRICAN INTERNATIONAL CONFERENCE IN AUGUST 2016

In August 2016, and as Fifth African International Palliative Care Conference which took place from the 16th to 19th August 2016 at Speke Resort and Conference Centre, Munyonyo in Kampala, Uganda the Open Society Foundations (OSF), Open Society Initiative for Eastern Africa (OSIEA) and Open Society Initiative for Southern Africa (OSISA) three important workshops, in an effort to improve access to palliative care and controlled medicines for pain relief. The workshops are:

- i. ***Strategic advocacy for palliative care: lessons from the field of health and human rights;*** This workshop aimed at strengthening the field of strategic advocacy for palliative care by drawing on the experiences, successes, of and lessons learned by other human rights and health movements and from previous advocacy for palliative care and pain relief.
- ii. ***Legal needs and support for palliative care patients and families;*** This workshop aimed to bring together legal practitioners, human rights advocates, national human rights commissions and palliative care providers to exchange models, lessons and best practices for the integration of legal aid/support into palliative care services.
- iii. ***Access to controlled medicines workshop.*** This workshop aimed to bring together those working on different aspects of drug policy as it relates to controlled medicines and substances, to engage in meaningful reflection and discussion of the strategies for effecting a balance between the availability of controlled medicines for medical purposes and the prevention of abuse and diversion at the international, regional and national levels.

The strategic advocacy workshop was attended by 159 delegates from 27 countries; the workshop on legal support for palliative care patients and their families was attended by 87 delegates from 16 countries and the access to controlled medicines workshop was attended by 69 delegates from 19 countries.

The three workshops provided the first time opportunity to bring together the key, yet diverse stakeholders to share lessons and best practices for the integration of palliative care and pain relief as a human right in main stream health systems in Africa. Workshops also enabled stakeholders to explore more innovative approaches for strategic and effective palliative care advocacy, drawing lessons from other fields of health, human rights and the media, in an effort to accelerate the achievement of global and regional commitments on palliative care and pain relief, especially, the 2014 World Health Assembly (WHA) Resolution on Palliative Care. Discussions were also key in renewing commitment from delegates towards ensuring access to justice by patients who need palliative care and their families.

Six months after the conference, APCA followed up all delegates to establish how the 3 workshops have impacted on their work. Below are some of the highlights on the feedback that APCA received;

Feedback on the strategic advocacy for palliative care workshop; lessons from the field of health and human rights

- i. Some organizations were already undertaking projects in line with strategic advocacy prior to the workshop. At the workshop, lessons and best practices were shared and have been adapted to further improve these programs. Key lessons and best practices shared and utilised have been around the areas of; planning, creating long lasting messages, setting targets, implementation and monitoring. **(KEHPCA- Kenya).**

- ii. Some delegates were able to share the knowledge and skills attained through Continuing Medical Education (CME) sessions with work colleagues, hence a bigger team with some basic skills and experience in strategic advocacy for palliative care now exists at the facility, which makes the voice for palliative care advocates bigger. **(Kabale Regional Referral Hospital - Uganda).**
- iii. In Kabale Regional Referral Hospital, there was an increase in the number of palliative care patients from 358 to 450 patients within 6 months after the conference. This increase is majorly attributed to increased awareness of the palliative care services at service centres as well as increase in home visits to reach out to the bed ridden patients. The team that was sponsored to participate in the three workshops picked some of the strategies learnt to reach out to more patients. **(Kabale Regional Referral Hospital – Uganda).**
- iv. Some facilities reported an improvement and ease in drug procurement, availability and supply, which has led to the number of patients accessing palliative care medicines increasing. **(Kabale Regional Referral Hospital Uganda, Busia Hospice - Kenya).**
- v. In Zimbabwe, a core advocacy group that works closely with the national association and the Ministry of Health has been formed following the lessons and boost from the workshop. **(Independent Consultant – Zimbabwe).**
- vi. Some organizations used the knowledge attained in the workshop to include an advocacy strategic intent/objective within their long term organizational strategy plan with a specific focus on the May 2014 World Health Assembly (WHA) resolution on strengthening palliative care. Plans are underway to employ staff with strong advocacy skills to do the advocacy work of the organization. More so, in the same organization, a monitoring and evaluation personnel has been brought on board to improve data management especially at patient level for improved strategic decision making. **(Island Hospice – Zimbabwe).**
- vii. Some organizations have already engaged the highest policy making level, the national Ministry of Health and Child Care (MOHCC) specifically with the permanent secretary for health about the inclusion of palliative care within the health system and engagement with HOSPAZ about their core role in pushing the strategic agenda of palliative care in the country. Follow up meetings have been held with heads of relevant MOHCC departments. **(Island Hospice – Zimbabwe).**
- viii. Island Hospice was privileged to speak at the Community Working Group for Health Annual National Meeting. The MOHCC was present including the health economist that budgeted for the latest National Health Strategy. They got an opportunity to show the video on palliative care?; <https://goto.gg/24223> and discussed the cost of not caring, which was posed during the workshop at the APCA conference. This was an opportunity to further disseminate information on and advocate for the need to integrate palliative care into the health system in Zimbabwe. **(Island Hospice – Zimbabwe).**
- ix. “I would say, the strategic advocacy workshop helped me personally in the first place. I came to the conference when I was working at the main office as district program coordinator but through the knowledge and skills attained during the APCA conference and through the advocacy sessions, in November, 2016 I was moved to Tisungane clinic where there is an ART clinic, Kaposi Sarcoma clinic, Cervical Cancer clinic and palliative care clinic. My main role is taking charge of all these clinics including supervising the teams” **(Davie Mpate, Dignitas International; Zomba Central Hospital, Malawi).**

- x. “The workshop renewed the enthusiasm for pushing for change”, **Jenny Hunt, Independent Consultant, Zimbabwe.**

Feedback on the access to controlled medicines workshop

- i. Countries have been able to borrow and use some of the knowledge and skills from this workshop to overcome barriers to access to controlled medicine in their own countries. Kenya is utilizing the “tactics” learned to strengthen the advocacy on access to controlled medicine. Kenya Hospices and Palliative Care Association (KEHPCA) planned to organize for a stakeholders meeting to address the issues on access to controlled medicines as well as the need to develop a palliative care policy. **(KEHPCA - Kenya).**
- ii. Delegates also reported an improvement in reporting on morphine consumption, which was previously being done quarterly and is now being done on a monthly basis hence further showcasing the palliative care work being done at the facility to the hospital management **(Kabale Regional Referral Hospital – Uganda).**
- iii. Health facilities learned and refreshed their knowledge and skills on the management of controlled medicines and have continued to successfully maintain stock cards, send morphine consumption reports monthly to the relevant bodies/departments. For the case of Uganda, the Palliative Care Association of Uganda (PCAU) is using mHealth technology as well as maintaining the supply of the medications at the facilities. This therefore encourages proper accountability of the controlled medicines, but also ensures a steady and accurate supply at the facilities, and improved access by the patients. **(Kabale Regional Referral Hospital, Uganda; Zomba Central Hospital - Malawi)**

Feedback on legal needs and support for palliative care patients and families workshop

- i. Organizations have used the knowledge attained from this workshop to expand the existing legal projects in their countries, as well as pick sustainability lessons and practices. **(KEHPCA, Kenya).**
- ii. The information shared in this workshop specifically the APCA/PCAU/UGANET model has been shared with Ministry of Health and the Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) to adapt and expand care and support for patients in Zimbabwe. The WHA resolution has been especially helpful to justify our determination to improve care although the implementation of these is still very slow. **(Independent Consultant, Zimbabwe).**
- iii. The APCA conference and workshop on legal needs of palliative care patients emphasized the need to follow up palliative care clients who are referred to either the social workers or the probation officers to resolve their non - medical needs. That was a lesson that was picked through the workshops and has been implemented. **(Kabale Regional Referral Hospital, Uganda).**
- iv. Organizations that did not have the legal service for patients used the knowledge acquired in this workshop to start conversations with legal service providers about the possibility of partnering to provide pro bono services to palliative care patients. Evangelical Lutheran Church of Tanzania (ELCT) met with Legal and Human Rights’ Centre (LHRC) and had several discussions in line with partnering. This looks like a possible partnership and ELCT is working on the referral forms to ensure proper documentation and reporting and even before the formal documentation is done, 3 referrals of palliative care patients with legal cases have been made to LHRC. **(ELCT, Tanzania).**

- v. Organizations have partnered with the legal service providers as is the case of Island Hospice and Legal Resources Foundation to handle the legal issues among palliative care patients. There are preliminary talks about training staff and caregivers on legal needs and support for palliative care patients and families. **(Island Hospice, Zimbabwe).**
- vi. It has boosted our legal arm of care in that the intensified legal sensitizations have created awareness and demand for legal aid. This has helped us to see more clients in the legal clinic and sometimes have two clinics in a month instead of one per month that we used to have. **(Alice Businge, MildMay Uganda).**
- vii. Palliative care patients with legal needs have been assisted following the knowledge and skills attained from the workshop. **(Paris Wandera, Busia Hospice, Kenya)**

With the above highlights, it is indeed very clear that these were practical and useful workshops that have made a difference in the lives of patients, the work and the countries of the delegates that attended them. APCA continues to be in touch with these delegates and shall continue to share the highlights of the impact of the strategic advocacy workshops as they unfold.