PALLIATIVE CARE: a moral AND economic imperative?

Seeking robust evidence to challenge policy-making priorities in Malawi and beyond

Evidence of health systems savings through early access to palliative care in high-income countries has resulted in significant expansion in services. Limited research suggests that access to palliative care in low income settings conveys cost benefits at household level, although this research is at an early stage.

On 2 March 2018, national and international experts in clinical care, public health and policy met in Lilongwe, Malawi, to review the Patient and Carer Cancers Costs (PaCCCt) survey. Once finalised, this survey will be used to measure and describe financial and wellbeing trajectories for patients and families from the time of diagnosis of advanced cancer, providing important evidence about the economic burden on households and the impact of palliative care.

To start the day expert speakers delivered keynote plenaries, informing and challenging the priorities and practices of policymakers and palliative care professionals, providing vital guidance for future action.

Values, costs and cancer: Professor Joseph Mfutso-Bengo, College of Medicine

Principles of a new concept called 'VED mapping'(values and evidence-informed decision making) were outlined, considering values as a forgotten pillar in health systems strengthening. Consideration of values and evidence leads to good decision making when developing policies around cancer care. VED mapping promotes professionalism and resilience in health systems. Data on the burden of household costs is part of the necessary evidence required when adopting this approach as services for patients affected by cancer are deveoped.

Cancer and the EHP: health economic perspectives from the Ministry of Health: Dr Gerald Manthalu, Ministry of Health

The aim of the EHP is to ensure timely universal free access to a quality Essential Health Package, irrespective of ability-to-pay, to all the people in Malawi. Palliative care is not yet included in the EHP within the Health Sector Strategic Plan (HSSP) 2017-2022. In this presentation the criteria and guiding principles for the EHP in Malawi were outlined. Total health expenditure is very low in Malawi ($39 per capita), with continuing donor dependence. Priority areas are decided on the basis of data on QALYs and DALYS with funding shortfalls in a number of areas. Costing evidence is needed to inform service development. Ongoing health system changes are also required to deliver the EHP.

<u>What is the value of palliative care in low income settings?</u>: Professor Liz Grant, University of Edinburgh

Significant progress in palliative care has been achieved in Malawi over the last fifteen years though access to services remains limited particularly for those living in rural areas. Household costs borne by patients and families affected by life limiting illnesses can be catastrophic and such costs disproportionately affect the poorest. Long-term consequences can be severe, entrapping future generations. Where palliative care is provided, patients are supported to receive appropriate pain-relieving treatment, enabling them and/or their carers to return to work. Patient centred counselling reduces discrimination, promotes social inclusion through involvement in activities of daily living and provides families with information to assist with future treatment decisions, whether to sell assets and inheritance planning.

<u>Perspectives on palliative care and poverty from the global advocacy movement</u>:Eve Namisango, African Palliative Care Association

Palliative care is a fundamental human right, integral to Universal Health Coverage, and required to relieve the severe health related suffering experienced by some 61 million people worldwide. It is key to achieving the Sustainable Development Goals (SDGs) : 'no poverty', 'zero hunger' and 'gender equality' (as women are disproportionately affected), and is directly relevant to 8 of the 13 targets on health.

Eve addressed the following myths about palliative care:

- MYTH: Palliative care is a 'do-nothing' option at the end of life." → REALITY Palliative care begins on diagnosis with a life-limiting illness, enables patients to return to work and protects their families' future.
- MYTH: Palliative care is an expensive luxury." → REALITY Palliative care can be a cost-effective option
- MYTH: Palliative care is only for the elderly." → REALITY Palliative care is required for people of all ages

Following the keynote speeches, Ewan Tomeny (health economist, Liverpool School of Tropical Medicine) presented a brief history and overview of patient cost collection, using the example of the WHO patient cost tool for TB from which the PaCCCt survey is derived. Jane Bates (palliative care physician, College of Medicine, PI, Liverpool School of Tropical Medicine) provided background information on the early process of development of the PaCCCt survey. Meeting delegates then divided into four groups to review and provide feedback on the PaCCCt survey. .

<u>Concluding remarks</u>: Professor Bertie Squire, Liverpool School of Tropical Medicine

Families in Malawi living at the margins bear huge cost burdens when a diagnosis of cancer is made. Provision of palliative care is vital for responsive health systems in Malawi and beyond. There is growing evidence to support its social and economic benefits as a poverty reduction strategy, benefitting both households and the health system. This is a crucial moment as we consider how this information will feed into the EHP. Harnessing input from this policy making forum in the developmental stages of the research process provides a model for future practise. Results of this research will be presented back to this group to support Malawi as it moves towards Universal Health Coverage.

"Palliative care offers enormous transformation which, when embedded within the health system, can be delivered at minimal financial cost." *Professor Liz Grant, University of Edinburgh*

"Only by fully understanding the origins, trends, extent and drivers of these patient costs can steps be made to effectively curtail them." *Ewan Tomeny, Health Economist, Liverpool School of Tropical medicine*

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"It is more costly not to have palliative care in low resource settings: we need evidence."
Eve Namisango, research manager, African Palliative Care Association

Name	*Details*
Speakers	
Lameck Thambo	Executive Director, Palliative Care Association of Malawi (PACAM)
Joseph Mfutso-Bengo	Professor of Bioethics and Health Social Sciences, College of Medicine, University of Malawi
Gerald Mantulu	Health Economist Deputy Director of Planning, Ministry of Health, Government of Malawi
Liz Grant	Director of the Global Health Academy, Professor of Global Health, University of Edinburgh
Eve Namisango	Research Manager, African Palliative Care Association
Ewan Tomeny	Health Economist, Centre for Applied Health Research and Delivery, Liverpool School of Tropical Medicine (LSTM)
Jane Bates	PhD student, LSTM Clinical Lecturer, Department of Family Medicine, College of Medicine
Bertie Squire	Professor of Clinical Tropical Medicine Director, Centre for Applied Health Research and Delivery, LSTM
Delegates	
Adamson Muula	College of Medicine
Leo Masamba	Ministry of Health
John Parks	College of Medicine
Cornelius Huwa	Ministry of Health / Palliative Care Support Trust
Hastings Chiumia	Ministry of Health
Jonathan Chiwanda	Ministry of Health
Tulipoka Soko	Ministry of Health
Immaculate Kambiya	Ministry of Health
Lillian Maliro	Ministry of Health
Andrew Dimba	Ministry of Health
Bowen Kapondera	NHSRC
Mirriam Shaba	Malawi College of Health Sciences
Micrina Mwandeti	Lighthouse

Agnes Moses	Partners in Health
Maria Chikasema	UNC
Duncan Kwaitana	Nurses Organisation of Malawi
Esmie Mkwinda	Kamuzu College of Nursing
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