

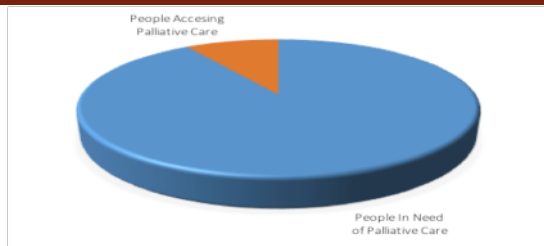


ACCESS TO PALLIATIVE CARE

Palliative care improves the quality of life of patients through early identification, correct assessment, treatment of pain and the provision of psychosocial, spiritual support. Despite Uganda's achievements, access to palliative care services is limited. In 2011, Uganda accepted a recommendation to create a National Health Insurance Scheme (NHIS), however, the NHIS bill doesn't include palliative care.

90% OF UGANDANS IN NEED OF PALLIATIVE CARE CANNOT ACCESS IT (MoH, 2015b). Of the 3,490,000 people in Uganda in need palliative care, only 10% of them can access it (APCA, 2015). The palliative care services provided are predominantly medical yet effective palliative care requires holistic, culturally appropriate medical, mental, spiritual care and psychosocial support provided by a multi-disciplinary team and in all settings.

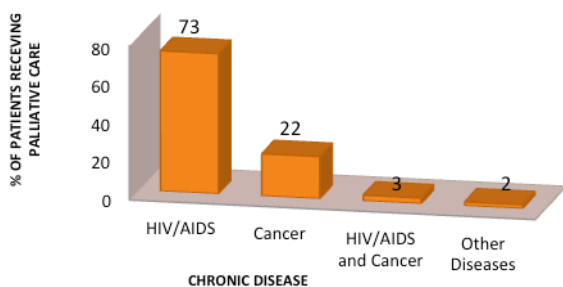
UGANDANS ACCESSING PALLIATIVE CARE



Source: MoH, 2015b

THERE IS A GROWING NEED FOR PALLIATIVE CARE IN UGANDA, PARTICULARLY FOR PATIENTS WITH CHRONIC DISEASES. Patients with cancer are vulnerable to pain, those with AIDS are vulnerable to pain and opportunistic infections arising from a weak immune system, other end stage diseases are progressive, chronic and non-treatable, requiring pain management. According to the most recent survey, 80% of the 16,526 patients who died of cancer in Uganda had moderate to severe pain and at least 65% of cancer patients in Uganda require opioid medication (Treat the Pain 2010). 50% of the 112,065 people who died due to HIV related causes had moderate to severe pain. (Treat the Pain 2010). 73% of those who need palliative care are patients with HIV, 22% are those with cancer, 3% are those with both HIV and Cancer and 2% are those with other diseases (WHO, 2016).

PALLIATIVE CARE AND CHRONIC DISEASES IN UGANDA



Source: WHO, (2016)

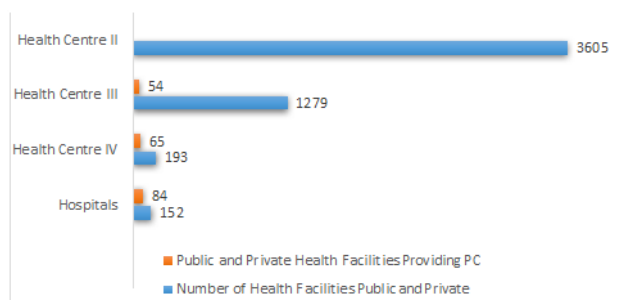
This number is likely to increase given the increasing incidences of life limiting chronic diseases due to

lifestyle changes, nutritional preferences, infections and an increasing sedentary work pattern (APCA, 2011).

THE LIMITED ACCESSIBILITY OF PALLIATIVE CARE IS WORSE IN RURAL AREAS. 90 districts have palliative care services (MoH, 2015b). However, in these districts, palliative care services are only available in a few health facilities such as referral hospitals, health centre IVs and health centres III. Only 4.8% of hospitals offer palliative care services (MoH, 2015a). Most people rely on referrals to non-government organisations and the National Referral Hospital.

There is even less access in rural areas and over 80% of all palliative care services are offered in urban areas. Health centre IIs, which are closer to the population in rural areas, often lack palliative care services.

ACCESS TO PALLIATIVE CARE IN HEALTH



Source: APCA, 2015 & MoH, 2012.

UGANDA LACKS A COMPREHENSIVE NATIONAL POLICY ON PALLIATIVE CARE. The Ministry of Health, in partnership with civil society organisations providing palliative care, has drafted a National Palliative Care Policy to provide a comprehensive framework for the integration of palliative care services into the health care system and to guide the sustainability of palliative care service delivery. The policy is yet to be passed. Doing so would guide and streamline the planning, budgeting, implementation and evaluation of palliative care services in the country.

LACK OF ACCESS TO ESSENTIAL MEDICINES FOR PALLIATIVE CARE. Despite the government's commendable strides in providing free oral morphine to Ugandans through a public private partnership with Hospice Africa Uganda, other essential medicines that should accompany morphine like laxatives and adjuvants are not easily available.

LIMITED FINANCING OF PALLIATIVE CARE HINDERS ITS PROVISION AND ACCESS. In 2015/16, public financing for palliative care was only 155 million Uganda shillings

(approximately 46,000 USD) (MoH, 2016). Yet the cost of providing palliative care per patient is 86,000 Ush (26 USD) per person per week. Palliative care services are mostly provided by non-profit organisations, which is unsustainable.

Question: What measures have you taken to increase financing for palliative care?

THE INADEQUATE INVESTMENT IN HUMAN RESOURCE FOR PALLIATIVE CARE RESULTS IN LIMITED ACCESS TO PALLIATIVE CARE. Despite efforts to integrate palliative care in the medical and nursing curricula of health training institutions in Uganda, not all health teaching institutions have courses on palliative care due to the lack of trained tutors and lecturers. Training is only provided by civil society organizations and Makerere University who have trained only 8,000 trained professional and non-professional palliative care practitioners and prescribers for the whole country (WHO, 2013). Furthermore, while the government has accredited and recognizes training in palliative care at diploma and degree level, the Health Services Commission and health professional councils do not recognize palliative care practitioners as specialists, curtailing their motivation to undertake specialised palliative care training. This poses a challenge to the long-term provision of holistic and comprehensive palliative care services.

IT IS UNCLEAR WHETHER THE PROPOSED NATIONAL HEALTH INSURANCE SCHEME WILL COVER PALLIATIVE CARE. During Uganda's 2011 UPR, Uganda accepted to create a national health insurance scheme for the poor in order to achieve universal health coverage. While the government has drafted a National Health Insurance Bill, it is not clear that palliative care will be provided in the basic benefit package.

Question: Will the proposed National Health Insurance Scheme Cover Palliative Care in the basic essential package?

COLLECT AND MAKE PUBLICLY AVAILABLE DISAGGREGATED DATA ON PALLIATIVE CARE, NEEDED FOR DECISION MAKING AND RESOURCE ALLOCATION. During Uganda's 2011 UPR, Uganda accepted to take steps to put in place well functioning health information systems, which combine disaggregated data. Despite the government's commendable steps to develop data collection tools for palliative care, there is no readily and publicly available data on the provision of palliative care nor on the number of people living with moderate or severe pain, disaggregated by age, income, rural/urban. Yet this data is needed to guide

decision-making, and resource allocation for palliative care services.

UGANDA LACKS A COMPREHENSIVELY FUNDED AND FULLY AUTONOMOUS CANCER INSTITUTE. The number of deaths caused by cancer have increased 100% since 1990 (MoHa, 2015). Yet only 20 oncologists serve a population of 34 million and the demand for these experts is growing with more than 60,000 new cases of cancer in Uganda alone. Uganda Cancer Institute (UCI) is the only facility that provides specialized treatment for cancer and it lacks adequate resources. UCI received UGX 42.885 billion for 2016/17 (MoH 2016). As an autonomous body, it could receive better funding from internal and external sources.

RECOMMENDATIONS

Fast track the passing of the Palliative Care Policy.

Review the essential medicines list to include palliative care medicines other than morphine.

Allocate adequate funds for palliative care within health sector budget.

Train palliative care providers at all levels and recognise palliative care as a medical, nursing and allied health worker's specialty by the Health Service Commission.

Ensure palliative care services are provided for in the National Health Insurance Scheme.

Generate, collect and disaggregate data on palliative care and distribute to stakeholders.

Establish the Uganda Cancer Institute as an autonomous body by an Act of Parliament.

ABOUT THIS FACTSHEET

This factsheet was prepared by the Initiative for Social and Economic Rights (ISER), Palliative Care Association Uganda and the African Palliative Care Association in light of Uganda's appearance before the Human Rights Council's Universal Periodic Review (UPR) in 2016. It accompanies the joint submission to the UPR on palliative care endorsed by palliative care practitioners.

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